

1 **Wednesday, 23rd June 2021**

2 **(10.00 am)**

3 Anonymity Order

4 **SIR BRIAN LANGSTAFF:** Now, our first witness this morning,  
5 as you know, is anonymous. He is witness W3044 and,  
6 in his case, as in the case of others who have  
7 anonymity, I shall read out the order which applies in  
8 his case.

9 I order that the name and address of  
10 witness W3044 and any other identifying information,  
11 such as the witness's image or a description of their  
12 appearance, cannot be disclosed or published in any  
13 form unless express permission is given by me or by  
14 the solicitor to the Inquiry acting on my behalf.

15 Witness W3044 must be referred to only as Mr BC.  
16 This order remains in force for the duration of the  
17 Inquiry and at all times thereafter, unless otherwise  
18 ordered, and I may vary or revoke the order by making  
19 a further order during the course of the Inquiry.

20 So Mr BC, Mary will now ask you to take the  
21 oath.

22 **WITNESS W3044 - MR BC (affirmed)**

23 **Questioned by MS FRASER BUTLIN**

24 **MS FRASER BUTLIN:** Mr BC, you have severe haemophilia A.  
25 Is that right?

1

1 very bizarre side effect that I literally forgot how  
2 to walk. You know, I had only been in bed for three  
3 to four days, and I could not get up and put one foot  
4 in front of the other. And so that -- I only  
5 effectively had the treatment for the one bleed.

6 **Q.** Your bleeding as a severe haemophiliac caused severe  
7 problems with your education?

8 **A.** Yes.

9 **Q.** What can you tell us about your education up to the  
10 age of 11?

11 **A.** So my education up to the age of 11 was really very,  
12 very limited. Having had inhibitors, a typical bleed  
13 would last anywhere between, shall we say, 10 and  
14 14 days. And then you would gradually start to  
15 re-mobilise and then the process would repeat again.

16 So I, aged -- I think at age six I went to  
17 school for three days in the year. And then in the  
18 following year, I think I probably went for about nine  
19 days.

20 So, behind the scenes, I was very, very  
21 fortunate in that to make up for, I guess,  
22 haemophilia, I was born kind of with a bit of a brain,  
23 really, and was quite kind of intelligent and  
24 interested as a kid. So the local kind of teaching  
25 authority initially brought in a private tutor for me

3

1 **A.** Yes, I do.

2 **Q.** And you were diagnosed at about age 3 after you broke  
3 your leg?

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

5 **Q.** And your care was then transferred to Cardiff under  
6 Professor Bloom.

7 **A.** Correct, yes.

8 **Q.** You developed an inhibitor and so you don't recall,  
9 I think, having any treatment apart from in 1975?

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

11 **Q.** And in 1975 you were admitted to hospital for some  
12 experimental treatment?

13 **A.** Yes.

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

15 **A.** I was led to believe that the treatment, I was  
16 possibly the first person in the UK to get it, and  
17 about probably the tenth in the world to get it.  
18 Apart from that, being aged about six at the time, my  
19 memory is obviously a little hazy.

20 My guess would, because I couldn't take  
21 Factor VIII at the time, it was probably some kind of  
22 experimental bypassing agent. The treatment was  
23 successful in the sense that it kind of worked for  
24 reducing the bleed and the length of time that I had,  
25 effectively, to spend laid up. However, it had the

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1 for two hours a day, and that seemed to be going  
2 reasonably well but everyone thought that that really  
3 wasn't enough. And of course also you weren't having  
4 a social interaction of the children of the same age  
5 that was obviously so important to someone like me.

6 So around about '78 it was beginning to be  
7 suggested that I might go to perhaps a school  
8 somewhere that would be able to take my condition, and  
9 so on and so forth. There was one school I know that  
10 was possibly recommended in Bristol but Prof Bloom  
11 didn't like that one very much, and so it was decided  
12 that I would board at Treloar's from '79.

13 **Q.** And you said just a moment ago that Prof Bloom didn't  
14 particularly like the one in Bristol?

15 **A.** Yes.

16 **Q.** How influential was he in having you go to Treloar's?

17 **A.** So I was born in a Welsh mountain valley town, really,  
18 and my parents were very kind of old-fashioned in some  
19 sense. They were very stoic. We never talked about  
20 anything important. And consequently people in  
21 authority, teachers, doctors, were kind of -- like  
22 their word was, in some sense, kind of set.

23 So my mother in particular thought that, you  
24 know, Prof Bloom was fantastic and, you know, he'd got  
25 me into this school and so on and so forth. So he --

4

1 whatever he would have recommended, my parents would  
 2 have said yes to, I think.  
 3 **Q.** And you were at Treloar's until 1987 --  
 4 **A.** Yes.  
 5 **Q.** -- when you were age 18?  
 6 **A.** Yes, just shy of 18, yes.  
 7 **Q.** And you've described Treloar's as transformational for  
 8 you?  
 9 **A.** Yes. I mean, as a -- you know, a 6 to 9-year old  
 10 child who never, effectively, left the house, to  
 11 suddenly actually start interacting with other  
 12 children of the same age, and of course who had the  
 13 same condition as you, was kind of transformational,  
 14 really. It was eye opening, you know. And I think  
 15 I said in my statement it was a very kind of 'can do'  
 16 environment, where, "Yeah, we can do that."  
 17 So certainly my first several years at Treloar's  
 18 were, you know, very kind of eye opening and  
 19 transforming.  
 20 **Q.** When you were arrived at Treloar's, you said in your  
 21 statement that you didn't immediately receive  
 22 treatment.  
 23 **A.** Yes.  
 24 **Q.** When did you start treatment, as far as you know?  
 25 **A.** So obviously because of the inhibitors -- I had

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1 10 July 1980 and the second substantive paragraph:  
 2 "I have had some very good results with Autoplex  
 3 for knee and elbow bleeds in two of our lads with high  
 4 response inhibitors, neither of whom have [anamnesic]  
 5 responses of any significance.  
 6 "I would be very keen to treat [his] bleeds with  
 7 this substance particularly as we have such good  
 8 documentation of the behaviour of bleeds into his  
 9 knees when treated with immobilisation alone.  
 10 "I wonder whether you would agree to this?"  
 11 And I think you have then seen the response --  
 12 **A.** I've seen the response, yes.  
 13 **Q.** -- that would suggest that Professor Bloom was  
 14 content --  
 15 **A.** Happy with that.  
 16 **Q.** -- with that.  
 17 In the summer or maybe the autumn of 1980, it's  
 18 not entirely clear, were your parents aware of the  
 19 Autoplex treatment to be given to you?  
 20 **A.** Again, I personally -- my parents never spoke to me at  
 21 all about this, so I initially would have said no, but  
 22 scanning through my medical records, I think I have  
 23 seen correspondence from Dr Aronstam asking my parents  
 24 whether they would want me to go on an Autoplex trial.  
 25 **Q.** What we have in your records, and you can tell us

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1 high-level responding inhibitors, which meant that  
 2 they only had a certain number of doses that they  
 3 would be able to give me, so they had to be the saved  
 4 for very life-threatening bleeds. So I estimate  
 5 that I had been in the school probably for about  
 6 a year. So I would say something like late '80. The  
 7 new set of inhibitor-bypassing agents were coming onto  
 8 the market and in my statement, which was correct at  
 9 the time, I have now managed to find some records, and  
 10 there is evidence of a letter from Treloar's to  
 11 Cardiff or possibly Cardiff to Treloar's, I think,  
 12 saying yes -- it was from Prof Bloom saying, "Yes,  
 13 I have no objections to him going onto Autoplex", and,  
 14 you know, in some sense I can't remember the actual  
 15 wording of the letter, but it said something like, you  
 16 know, "We were very lucky to get one free dose, and we  
 17 can't afford it", basically. So no problems.  
 18 **Q.** We've got the letter from Dr Aronstam to  
 19 Professor Bloom, which pre-dates the letter I think  
 20 that you have --  
 21 **A.** That one, yeah.  
 22 **Q.** -- which unfortunately we don't have to display, but  
 23 we can look at the letter from Dr Aronstam.  
 24 TREL0000167\_016, please, Soumik. Thank you.  
 25 We can see there the letter is dated

6

1 whether this is what you've seen or whether it was  
 2 something else, is TREL0000173\_083. And it's a little  
 3 bit later in time, 8 December 1981.  
 4 **A.** Yes, I think that's the letter that I seem to have  
 5 remembered, flicking through the 500 pages of medical  
 6 notes.  
 7 **Q.** You see this discusses weekly injections of  
 8 Factor VIII rather than --  
 9 **A.** The Autoplex.  
 10 **Q.** -- Autoplex?  
 11 **A.** Yes.  
 12 **Q.** As far as you can recall, don't worry if you're not  
 13 entirely sure, do you think there was another letter  
 14 in relation to Autoplex or just this letter in  
 15 relation to Factor VIII?  
 16 **A.** I honestly wouldn't know, sorry. I'd have to go back  
 17 and try and find that in the notes.  
 18 **Q.** If we stay with this letter, December 1981, so some  
 19 time later --  
 20 **A.** Yes.  
 21 **Q.** -- there is this letter to your parents saying this.  
 22 "There has recently been a lot of new hope for  
 23 the treatment of inhibitors in haemophiliacs. Many  
 24 workers in Europe now claim to be able to lower the  
 25 level of inhibitors to factor VIII so that treatment

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1 for bleeding can be given as easily as if inhibitors  
 2 were not present.  
 3 "I wonder whether you would agree to my using  
 4 one of the newer methods on [him] in an attempt to  
 5 reduce the way his inhibitor resists to treatment. It  
 6 would then be possible to give him some very active  
 7 physiotherapy for his knee and hopefully a better  
 8 quality of life.  
 9 "The method would involve weekly injections of  
 10 factor VIII and the taking of several blood samples at  
 11 various intervals. I have, of course, spoken to  
 12 Professor Bloom about this and any use of such methods  
 13 would, of course, be a combined operation."  
 14 It appears, after this letter, looking at your  
 15 records, that you then did undergo a course of immune  
 16 tolerance treatment in 1982 --  
 17 **A.** Yes.  
 18 **Q.** -- after the Autoplex?  
 19 **A.** Yes. I think the idea was that with the Autoplex and  
 20 the FEIBA and the porcine, which I tried, and the  
 21 probably Factor IX that I would have tried, because  
 22 I then had some back-up they could then go with the  
 23 immune tolerance. They had alternative, kind of,  
 24 treatments to give me.  
 25 **Q.** And we can see that on TREL0000173\_019, please.

9

1 We have a page of what the Inquiry has seen in  
 2 relation to another witness that appeared to be an  
 3 equivalent to the school report that would go home,  
 4 and one of the pages was the medical page.  
 5 **A.** Mm-hm.  
 6 **Q.** Do you recall having anything like that to take home?  
 7 **A.** Yes and, scouting through my medical records, I have  
 8 found forms that effectively were treatment forms that  
 9 on holiday periods, for example, I had to fill in. So  
 10 I have, you know, on the 27th of the 10th, 1983, given  
 11 six bottles of HP, dot, dot, dot, and so on and so  
 12 forth.  
 13 **Q.** I think we're slightly at cross purposes, apologies.  
 14 In terms of a school report, as in one page would be  
 15 about English and one page about maths --  
 16 **A.** Oh yes, sorry.  
 17 **Q.** -- and then at the back there would be a page about  
 18 medical or physiotherapy?  
 19 **A.** Yeah.  
 20 **Q.** Do you recall anything like that going home or taking  
 21 it home at the end of term?  
 22 **A.** I recall a school report. And as you said, obviously  
 23 English, maths and science were definitely there.  
 24 I think there probably was a short sentence or two  
 25 from the medical centre, yes.

11

1 It's a pupil review sheet, and we can see at the  
 2 bottom that it's dated 23 November 1983. And it  
 3 indicates that you were:  
 4 "Doing very well. No bleeds so far this term.  
 5 "Has been on the 'Tolerance Inducing protocol'  
 6 since April '82."  
 7 And that this had converted you from a high  
 8 responder to a low responder.  
 9 If we just pause there, other than the letter to  
 10 your parents in relation to the Factor VIII, do you  
 11 recall any discussion at all about any risks involved  
 12 in undergoing this treatment?  
 13 **A.** No.  
 14 **Q.** While we've got this document here, if we could just  
 15 zoom out again. We can see a note above the  
 16 handwriting:  
 17 "Parental involvement in medical care: Yes."  
 18 We've obviously seen the letter in 1981.  
 19 **A.** Mm.  
 20 **Q.** Are you aware of any other involvement of your parents  
 21 in relation to your care?  
 22 **A.** No.  
 23 **Q.** In relation to how often you received that Factor VIII  
 24 tolerance inducing protocol, could we have  
 25 TREL0000173\_004, please. Page 23 of that document.

10

1 **Q.** And that perhaps might look like this, as the back  
 2 page of the school report?  
 3 **A.** Yes, yes.  
 4 **Q.** So we have this from November 1982, and we can see  
 5 that, at that point, you were:  
 6 "Doing very well on the programme of 3 weekly  
 7 Transfusions with Factor VIII concentrate aiming at  
 8 neutralising his inhibitor level."  
 9 So in November '82 it seems you were receiving  
 10 three-weekly transfusions.  
 11 **A.** Monday, Wednesday, Friday.  
 12 **Q.** Monday, Wednesday, Friday?  
 13 **A.** Monday, Wednesday, Friday. Blood taken on a Monday.  
 14 **Q.** I just want to look at some of your other records to  
 15 explore some of the products that you were receiving,  
 16 particularly in 1983.  
 17 Could we have TREL0000170\_018, please. And  
 18 could we start at page 9, please. Thank you. So we  
 19 can see on the top left the date, 6 February 1983.  
 20 Then if we go down to "Units Material", we can see  
 21 there you were given Interhem.  
 22 **A.** Mm-hm.  
 23 **Q.** And then if we go to page 7, 12 February 1983, and  
 24 Interhem again.  
 25 Then if we go to page 1, 5 March 1983: high

12

1 potency Factor VIII.  
 2 Then page 11, we have a series of entries across  
 3 17 and 18 May: high potency Factor VIII, FEIBA,  
 4 Autoplex, Autoplex.  
 5 **A.** Mm-hm.  
 6 **Q.** Does that accord with your recollection of the  
 7 different products you received or, at the time, were  
 8 you unaware of what you were receiving?  
 9 **A.** Yes, that does -- yes, that strikes a chord, yes.  
 10 **Q.** Was there ever any discussion about the types of  
 11 product you would receive?  
 12 **A.** No, not really.  
 13 **Q.** You continued to receive the regular Factor VIII to  
 14 try to reduce your inhibitors?  
 15 **A.** Yes.  
 16 **Q.** And if we again go to another couple of records,  
 17 TREL0000173\_004, please, page 30.  
 18 We can see in the bottom right-hand corner  
 19 another of those medical reports. And we can see that  
 20 it's dated 19 June 1983:  
 21 "To neutralise his inhibitor level his programme  
 22 was stepped up to daily transfusions with Factor VIII  
 23 instead of the previous 3 weekly transfusions."  
 24 Does that accord with your recollection?  
 25 **A.** No. I don't remember going to daily prophylaxis, no.

13

1 **Q.** Do you positively remember that you didn't or do you  
 2 just not recall?  
 3 **A.** Oh no, definitely not. I just can't recall.  
 4 **Q.** Can't recall?  
 5 **A.** No. I mean, obviously you were -- you were having  
 6 a lot of injections and for whatever reason you were  
 7 part of the Autoplex trial, you were part of the  
 8 porcine trial, you were part of this, you were going  
 9 up, having blood taken for various levels, you were  
 10 having treatment, which may or may not have worked so  
 11 you were having another treatment. So that could  
 12 absolutely be true, but I cannot honestly remember or  
 13 recall going on daily prophylaxis.  
 14 **Q.** This seems to have happened at some point in the  
 15 summer of 1983.  
 16 **A.** Mm-hm.  
 17 **Q.** And if we go to the next page of the records, we have  
 18 a note dated 22nd June 1983 with the heading "AIDS".  
 19 I'm going to just read it out because the writing is  
 20 very difficult to read, and I think I've --  
 21 **A.** They're doctors, what do you expect?  
 22 **Q.** -- interpreted what it says:  
 23 "[Temperature] 36.1. No sign of [temperature]  
 24 for [more than a week] in the past.  
 25 "No throat" --

14

1 **SIR BRIAN LANGSTAFF:** "No rise in" --  
 2 **MS FRASER BUTLIN:** Sorry, "no rise" -- I failed at the  
 3 first hurdle, sir, apologies.  
 4 "No rise in [temperature] for [more than a week]  
 5 in the past.  
 6 "No Throat pains or difficulty in swallowing for  
 7 [more than a week] in the past.  
 8 "No shortness [and I think it probably means no  
 9 shortness of breath] for more than [one week] in the  
 10 past.  
 11 "No Diarrhoea for [more than a week] in the  
 12 past."  
 13 Then there's a star:  
 14 ""Cough for [more than] [I think it's two weeks]  
 15 in the past, yes, but can't remember when. Certainly  
 16 not during the past [three months]. This is contrary  
 17 to what he told us on 28/2/83.  
 18 "[Lymph] Nodes: very small [lymph note] on  
 19 [left] axilla (same finding as 28/2/83).  
 20 "No loss of weight."  
 21 The star, it says:  
 22 "Same Findings as on 28/2/83."  
 23 **SIR BRIAN LANGSTAFF:** It's difficult to interpret the --  
 24 certainly not contrary to what he told us on  
 25 28 February 1983, which is more than three months

15

1 before 22 June.  
 2 **MS FRASER BUTLIN:** It is, sir.  
 3 **SIR BRIAN LANGSTAFF:** So what is contrary, one wonders?  
 4 **MS FRASER BUTLIN:** One does wonder. And we can go there  
 5 if it would be of assistance, sir, but there is no  
 6 record that I can see in the clinical notes of  
 7 anything on 28 February 1983.  
 8 Perhaps it would be useful to see that exercise.  
 9 It's page 28 of this document, Soumik.  
 10 At the top we have what appears to be the either  
 11 9 or 1 February 1983, and then a record of  
 12 13 March '83.  
 13 **SIR BRIAN LANGSTAFF:** Yes.  
 14 **MS FRASER BUTLIN:** And the records do appear to be  
 15 chronological with nothing particularly out of place.  
 16 **SIR BRIAN LANGSTAFF:** Are these simply orthopaedic notes,  
 17 however?  
 18 **MS FRASER BUTLIN:** That's been flagged orthopaedic but, if  
 19 one continues down through that page, it's physio as  
 20 well, and it's also general clinical notes.  
 21 **SIR BRIAN LANGSTAFF:** Where are the general clinical  
 22 notes?  
 23 **MS FRASER BUTLIN:** If one carries on down, one can see  
 24 a note that includes "physio" at the bottom, and then  
 25 the next page is:

16

1 "Spring Term Assessment:  
2 "Bleeds ...  
3 "Haematology ...  
4 "Biochemistry ..."  
5 So it may be that we're missing something.  
6 **SIR BRIAN LANGSTAFF:** Yes, that certainly looks more  
7 general.  
8 **MS FRASER BUTLIN:** Similarly, if we go back a page, we  
9 also see haematology notes and references to having  
10 contacted Professor Bloom about bleeds. So it is  
11 obviously unclear, sir, exactly whether the notes are  
12 one set of notes or whether there are other documents  
13 that are missing. But what we have available to us  
14 we've not been able to identify a note in relation to  
15 28 February 1983.  
16 **SIR BRIAN LANGSTAFF:** Yes.  
17 **MS FRASER BUTLIN:** In June 1983, when we have this note  
18 headed "AIDS", were you aware of them undertaking any  
19 what might be termed "AIDS-related investigations" on  
20 you?  
21 **A.** No, no. Definitely not.  
22 **Q.** Then, if we can carry on in those notes to page 37 of  
23 the same document. Sorry, TREL -- thank you, Soumik.  
24 At the top of the page we've got entries for  
25 February '84 and March '84, where lymph nodes have

17

1 [I think it says] episodes?"  
2 **A.** Episode, yes.  
3 **Q.** It says:  
4 "Prophylaxis 8/1/84 - 23/1/84."  
5 And it gives a batch number for high purity  
6 Factorate. Then a series of batch numbers, and that  
7 it was high purity Factor VIII or ordinary Factor IX.  
8 Then it says:  
9 "Tolerance Inducing protocol stopped after the  
10 dose ..."  
11 Do you recall why the tolerance inducing  
12 protocol was stopped with you in March '84?  
13 **A.** I didn't. But, again, scanning through my medical  
14 records, I found a couple of correspondence again  
15 between Treloar's and Prof Bloom, basically I had  
16 a probably week or fortnight of pyrexia or spiralling  
17 temperatures, where my temperature would suddenly go  
18 up to 41 degrees and that's when they decided to stop  
19 the Factor VIII immune tolerance. For what reason,  
20 not automatically clear, whether I was seroconverting,  
21 whether I was being exposed to hep C, we don't know.  
22 I stopped the treatment and, I would guess,  
23 approximately after about two to three weeks,  
24 certainly I was back to normal, shall we say, the  
25 temperature had disappeared and I felt kind of, like,

19

1 been checked, and then 2 March '84 simply says:  
2 "Lymphocyte antibodies to Dr Smith."  
3 With nothing -- no further detail.  
4 Were you aware of any tests being sent out of  
5 Treloar's to anyone particular?  
6 **A.** No.  
7 **Q.** I just want to finish dealing with the tolerance  
8 inducing protocol. If we pick up in the same  
9 document, please, page 46.  
10 In fact, sorry, Soumik, if we could start on  
11 page 47.  
12 We can see a note which deals with tolerance  
13 inducing protocol, a little bit further down, please.  
14 "Started 26/4/82.  
15 "On 920 units at AD. High potency Armour  
16 Factorate. (See opposite pages for [batch numbers])."  
17 So we'll come to that in a moment.  
18 "Temporarily stopped after the dose on 28.3.84  
19 until further notice."  
20 If we go back a page to see the batch numbers,  
21 page 46, please.  
22 We can see the entry is on what appears to be  
23 4 April 1984. "Spring term Assessments", and we go  
24 down to the heading in the middle, please:  
25 "Material [batch numbers] related to pyrexial

18

1 fine.  
2 **Q.** And again, do you or from discussions with your  
3 parents, does anyone have a recollection of  
4 a discussion at that time about high temperatures and  
5 needing to stop the protocol?  
6 **A.** No. No. Unfortunately, high temperatures in the  
7 school were reasonably common. I mean if you put 200  
8 kids together, you know what you're like, you know,  
9 you get chickenpox parties and this that and the  
10 other. So if somebody got quite a bad chest infection  
11 it would go through the school. And shall we say  
12 perhaps -- to say this nicely -- the general health of  
13 the individuals at the school wasn't as good as the  
14 general population. So those chest infections or --  
15 became quite serious, and so it wasn't unknown for  
16 people to, you know, be in medical centre with --  
17 sounding like a rhinoceros trying to cough, basically.  
18 **Q.** I just want to look at one last record before I ask  
19 you some more general questions.  
20 If we could have TREL0000173\_061, please.  
21 This is a letter from 12 June 1984 from  
22 Dr Wassef to a doctor in the Netherlands where you  
23 were due to be going on holiday?  
24 **A.** Yes.  
25 **Q.** And we can see here that Dr Wassef has written that

20

1 your:  
2 "... inhibitor level varies between 7 and 11 New  
3 Oxford Units. We have been treating him with 50  
4 units/kg body weight of either Factor IX, FEIBA or  
5 Autoplex. For life-threatening bleeds or for bleeds  
6 not responding to the above measures, we have treated  
7 him with massive doses of Armour High Potency  
8 Factorate."

9 Is that also your recollection: that during  
10 certainly '84 --

11 **A.** Yes.

12 **Q.** -- that was the treatment you were having: massive  
13 doses of high potency Armour?

14 **A.** Yes. I stopped the immune tolerance in approximately  
15 March '84, but I continued to have Armour products,  
16 I would say, for probably about six further, seven  
17 further months, I would think. And again, going back  
18 to my medical records that you may have got -- it'll  
19 probably be the next slide, I'm probably  
20 pre-empting -- but I have certainly seen  
21 correspondence that I have had large doses of Armour  
22 for an ankle bleed in October of '84 which they  
23 flagged as suspicious because they thought I was  
24 putting it on, I think, in the nicest sense of the  
25 word.

21

1 **SIR BRIAN LANGSTAFF:** Mary, perhaps you can collect it.

2 **A.** I apologise in advance. I was quite late in going  
3 through these documents as they were all sent in  
4 a massive zip file so I couldn't even save them or  
5 drop them into a letter. So it ended up with me doing  
6 the high-tech thing of taking pictures of them on the  
7 phone. It's the "PS", Sarah, right at the bottom of  
8 that first page, I think, that I've turned over.

9 There's three lines right at the bottom.

10 **MS FRASER BUTLIN:** Oh gosh, yes.

11 I think it reads, sir:

12 "PS. Lately we have changed to heat-treated  
13 Factor VIII."

14 I'm afraid I'm struggling to read the rest. It  
15 appears to read something along the lines of:

16 "For patients who were receiving commercial  
17 Factor VIII, those who were on Lister, factor is  
18 unchanged."

19 But I would want to double check exactly what  
20 that said.

21 **SIR BRIAN LANGSTAFF:** Well, it appears on the face of it  
22 to be saying that those who had been having commercial  
23 concentrate would now get heat-treated commercial  
24 concentrate. Those who had been having NHS product  
25 would continue on NHS product.

23

1 Interestingly, at the bottom of that letter,  
2 which was a letter to Prof Bloom, it says, "PS. We  
3 have recently gone on to high purity". And the letter  
4 was dated, I think, from memory, something like  
5 mid-December, and the PS was something like, "For all  
6 those on commercial Factor VIII we have gone on to  
7 high ... we have moved them on to heat-treated. For  
8 those on Lister, currently unaffected, as you were".

9 **Q.** I'm afraid, sir, I don't think we have that to display  
10 today but I can make sure that it is available at  
11 a subsequent point.

12 You recall in your statement that Dr Dasani  
13 rotated to Treloar's as a doctor --

14 **A.** Yes.

15 **Q.** -- for a period. Is that right?

16 **A.** Correct, yes.

17 **Q.** And you've discussed his view of the treatment that  
18 was being given. What was it?

19 **A.** I do actually have a photocopy of the letter. If you  
20 can possibly read it at the very bottom but it's  
21 entirely up to you.

22 **Q.** I don't know if it would be useful if I read it out?

23 **A.** If you can possibly read it, sorry. The files ...

24 **Q.** We just need to make sure that the camera doesn't  
25 follow me.

22

1 **MS FRASER BUTLIN:** That's the sense of what I can read,  
2 sir, and it's dated 17 December 1984.

3 **SIR BRIAN LANGSTAFF:** It rather assumes that people were  
4 having just the one form of treatment.

5 **MS FRASER BUTLIN:** Indeed.

6 **SIR BRIAN LANGSTAFF:** At least so far as the NHS was  
7 concerned, but no distinction made with the word  
8 "commercial".

9 **MS FRASER BUTLIN:** Precisely.

10 **THE WITNESS:** If it's absolutely important to you, I do  
11 have it on my phone which is much clearer.

12 **MS FRASER BUTLIN:** We can pick it up at another point.

13 Thank you.

14 **SIR BRIAN LANGSTAFF:** We just have to be very careful,  
15 given you're anonymous.

16 **THE WITNESS:** No problems.

17 **MS FRASER BUTLIN:** Dr Dasani.

18 **A.** Oh sorry, yes.

19 **Q.** He, you said, rotated to Treloar's --

20 **A.** He did, yes.

21 **Q.** -- for a period, and you have suggested that you were  
22 aware of his view of the treatment that was being  
23 given?

24 **A.** Yes.

25 **Q.** What was that?

24

1 A. Dr Dasani and I had quite a strong relationship,  
2 really. He subsequently moved to Cardiff Haemophilia  
3 Centre, which is where I was based, and so we had  
4 a very strong relationship. And in 2000s we did kind  
5 of quite a lot of touring, giving medical talks about  
6 hepatitis C and the treatment that I was receiving  
7 then, so it was during those times, you know, when you  
8 were driving up and down the country on the M5 to give  
9 talks that you gradually talked about old times and  
10 nostalgia, and he was quite -- having just trained and  
11 come from Oxford, I think it was, he was quite shocked  
12 at the number of different batches that were being  
13 offered to the people or the haemophiliacs at  
14 Treloar's. And he said that he had mentioned that  
15 perhaps they should cut down the exposure and give  
16 only certain batches to certain, you know, students to  
17 minimise their risk.

18 He did hint in a kind of roundabout way as well  
19 that he thought that they shouldn't have been ...  
20 sorry, I have to pick my words carefully here.  
21 I think the Armour product was generally considered as  
22 dirty. And he was quite surprised that they were  
23 still using that one, in, let's say, 1983. That would  
24 be my general ...

25 Q. And did he talk specifically about the Armour issue or

25

1 time on 11.1.84 and was found to be positive."

2 Given what appears to be the case in relation to  
3 when the HTLV-III test was available, it would appear  
4 that 11 January '84 would have been a retrospective  
5 test.

6 We've got a note of both --

7 A. Sorry, when you say retrospective test, does that mean  
8 that in some sense samples had been stored? Blood  
9 samples of mine had been stored and then tested at  
10 a later date?

11 Q. That's what our current understanding would be and  
12 that was actually a question I wanted to ask you  
13 about. Were you aware --

14 A. No.

15 Q. -- of any samples being stored?

16 A. No, no.

17 Q. We've obviously got the medical record on 19 March and  
18 this letter on 22 March 1985. What's your  
19 recollection of how and when and what you were told  
20 about your diagnosis?

21 A. Sorry, can I just, before I answer that question --  
22 and bring me back to that, because I'll go off on  
23 a wild goose chase -- that does kind of explain a lot  
24 because obviously the 11/01 -- January -- sorry,  
25 11/01/84 is a long way from this, the date of this

27

1 is that something you're inferring?

2 A. He did talk directly about it.

3 Q. Because of course from what we've seen, you were  
4 receiving --

5 A. Yes.

6 Q. -- huge doses --

7 A. Yes.

8 Q. -- of high potency Armour.

9 A. Yes.

10 Q. You were infected with both HIV and hepatitis C.

11 A. Yes.

12 Q. And I want to just pick up in relation to the HIV to  
13 start with.

14 Could we turn to TREL0000173\_004, please.

15 Page 52.

16 We have an entry for 19 March 1985 and we've got  
17 a note "Virology", and we see:

18 "Anti-HTLV-III positive on 11.1.84."

19 And this picks up something of the strange  
20 wording that has been found in several witness' notes.  
21 And if I can then turn to TREL0000173\_051.

22 What we've got, the second paragraph down, it's  
23 a letter of 22 March 1985.

24 "He was anti-HBc and anti-HBs negative on  
25 19.9.84 and was tested for anti-HTLV 3 for the first

26

1 letter, which was March '85. So obviously if they had  
2 have stored blood, then that would have kind of like  
3 made sense.

4 **SIR BRIAN LANGSTAFF:** If I can just help on this, the  
5 conclusion to which, at the moment, I feel I should be  
6 bound to come is that there could not have been any  
7 testing or HIV or HTLV-III, as it was then known, as  
8 such, at a date prior to the scientific world being  
9 told there was such a thing as HTLV-III. You don't  
10 know it's there. If there isn't a test for it, you  
11 can't test for it.

12 A. Yes.

13 **SIR BRIAN LANGSTAFF:** But once the test became available,  
14 which was later in 1984, then it would be possible to  
15 use such a test to back-test any stored samples.

16 That's why at the moment, counsel thinks, suggests,  
17 that this is what must have been happening.

18 A. Yes.

19 **SIR BRIAN LANGSTAFF:** It's highly unlikely that we would  
20 not have heard of a test actually being used prior to  
21 the discovery of the virus or the identification of  
22 the virus, by that name.

23 A. Absolutely. Thank you.

24 **MS FRASER BUTLIN:** But understandably, the wording of this  
25 letter, which we've seen in a number of people's

28

1 medical records, is very strange, and I am conscious  
 2 that for many people it's been very confusing, but it  
 3 does appear to be relating to retrospective testing.  
 4 **SIR BRIAN LANGSTAFF:** If we just go back to the 004.  
 5 **MS FRASER BUTLIN:** Page 52.  
 6 **SIR BRIAN LANGSTAFF:** The note there is entirely  
 7 consistent with both.  
 8 **MS FRASER BUTLIN:** Absolutely.  
 9 **SIR BRIAN LANGSTAFF:** So it may be -- this is just pure  
 10 supposition for anyone to comment on in due course --  
 11 it's not a conclusion, it couldn't be, but it might be  
 12 that someone reading those notes or such notes would  
 13 have said it was tested positive then for the first --  
 14 that's the first record we've got, in effect.  
 15 **MS FRASER BUTLIN:** Precisely.  
 16 **SIR BRIAN LANGSTAFF:** Because that note doesn't say there  
 17 was an actual test conducted. Indeed, there wouldn't  
 18 be any point, really, in recording it on 19 March 1985  
 19 if there was already a record earlier in the notes  
 20 that it had been done on 11 January '84.  
 21 **MS FRASER BUTLIN:** Absolutely, sir.  
 22 **THE WITNESS:** Sorry, I suppose as well, you know, just  
 23 a point of interest in the whole idea of HTLV-III was  
 24 coming out in late '84 and so on and so forth, but  
 25 from memory, were there some -- there were some kind

29

1 swear on that. I think I was told individually. And  
 2 it was very much I don't really remember much after  
 3 that, whether some shock or kind of "oh wow" had  
 4 kicked in.  
 5 And I think -- I don't remember asking very many  
 6 questions about it, about what it meant, kind of,  
 7 I think I was probably in too much of a shock. But  
 8 I cannot recall being offered any form of counselling  
 9 at all. And Treloar's in some sense was a great  
 10 environment, but of course it also had a lot of  
 11 severely ill people with diseases. That meant their  
 12 life expectancy was 20, so death did kind of stalk  
 13 around the corridors a lot. And obviously when you  
 14 are young your cohort weren't really subjected to it,  
 15 but as you got to the finishing line, and you were 16,  
 16 17, 18, and your friends started going, so there was  
 17 never a counsellor and nothing like that was really  
 18 ever spoken about.  
 19 And of course you're giving effectively  
 20 a terminal diagnosis to a teenager, really. And  
 21 I know hindsight is a beautiful thing and we know that  
 22 in 2020 and we're all a bit more aware of mental  
 23 health than we were back in 1985, but surely that  
 24 doesn't sound quite right really, does it?  
 25 **Q.** And at that time, what was your understanding of AIDS?

31

1 of guidelines, I think, about how to reduce exposure  
 2 from either some clinical body like NICE or something  
 3 like that, particularly of -- I hate to use the  
 4 word -- "dirty" products, but there we go. And  
 5 obviously I'm still receiving Armour in October '84,  
 6 and of course I don't know the timelines of when those  
 7 diktats were issued by the Health Department or  
 8 whomever it might have been.

9 **Q.** Just in terms of your diagnosis, what's your  
 10 recollection of how you were told, when you were told?  
 11 What can you tell us about that?

12 **A.** It's interesting, isn't it, in that some people, that  
 13 is the thing that they will remember the most. And  
 14 for me, I think my mind has completely blocked it out.  
 15 It's just a box that does not want to be opened. So  
 16 when I was told, I could not honestly tell you. If  
 17 I had -- if you had to push me to it, I would guess  
 18 '85.

19 When, I have no idea. I have very little  
 20 recollection of the day apart from going up and being  
 21 told with someone who you're going to speak to quite  
 22 soon, and we went up effectively together to the  
 23 medical centre, and I cannot remember whether we were  
 24 told together or whether we were told individually.  
 25 I think some boys were told together but I wouldn't

30

1 **A.** I was going to be dead within two to three years.  
 2 **Q.** Had you been given any information prior to the  
 3 diagnosis?  
 4 **A.** Not really. Only the stuff that you'd picked up via  
 5 osmosis from the paper or from television or something  
 6 like that. And being kind of reasonably intelligent  
 7 and on the ball and so on and so forth, you kind of,  
 8 like, knew, really. You kind of knew.

9 **Q.** Were your parents told about your diagnosis?

10 **A.** I would not be able to answer that question.

11 **Q.** And have you ever been able to talk to them about it?

12 **A.** No. Is the honest answer. And it -- it's very  
 13 interesting, isn't it? If you were told you were  
 14 going to die in three years' time of a disease, there  
 15 would be effectively an outpouring of love and  
 16 sympathy and care for you as an individual. But in  
 17 1985 you were told that you probably were going to die  
 18 in two years, and in some sense the Government had set  
 19 up an environment which ostracised us, and basically  
 20 made us scared or made the general population scared  
 21 of us.

22 So rather than receiving any kind of support and  
 23 help or anything like that, we were effectively left  
 24 to go and die with our families in houses behind  
 25 locked doors. And that is something I think that, you

32



1 know, is very difficult, really.

2 **Q.** And it's a conversation you've never had with your  
3 parents?

4 **A.** No. If I'd said to them, "Dad, look, you know, I've  
5 got liver cancer", or something like that, or -- okay,  
6 we could have had a conversation about it. We've had  
7 conversations about haemophilia and about how it's  
8 going to affect you. But no, you couldn't talk much.  
9 And part of that, of course, was growing up in a Welsh  
10 valleys mountain town where everybody knew everybody  
11 else's business so you did not. And it was only in  
12 very late conversations with my dad, who is now, you  
13 know, effectively on the last leg, and has kind of  
14 been more amenable, shall I say, to having any form of  
15 talk with him, that you discovered that my parents did  
16 have some kind of, you know, words said to them in the  
17 village, basically.

18 **Q.** Did your diagnosis change your attitude to treatment  
19 for haemophilia at all?

20 **A.** No. I don't think so. As I've said in the notes,  
21 I think some, certainly some of the friends or  
22 haemophiliacs that attended the Alton Haemophilia  
23 Centre, as it was then, they decided that they never  
24 wanted more treatment because they thought a double  
25 dose would be worse. Whereas for me it was kind of

33

1 like, well, it's a virus, as soon as you've got it,  
2 you've got it, so treatment-wise, no.

3 **Q.** And as I said, you've also been infected with  
4 hepatitis C.

5 **A.** Yes.

6 **Q.** What can you tell us about that diagnosis, when you  
7 were told and what were you told about it?

8 **A.** Again, absolutely nothing. That's another completely  
9 blocked out kind of event.

10 **Q.** In terms of what happened after you left Treloar's,  
11 you obtained a degree in maths.

12 **A.** Mm-hm.

13 **Q.** And you were offered the opportunity to train as an  
14 actuary, I think initially?

15 **A.** Yes, correct.

16 **Q.** And you decided not to take up that place?

17 **A.** Correct.

18 **Q.** Why was that?

19 **A.** Um, okay. So that's ... in some sense, in 1982,  
20 the -- sorry, I beg your pardon, in 1992, when I was  
21 offered the government actuarial position -- or  
22 a government actuarial position, not the government  
23 actuarial position -- things hadn't really changed  
24 very much, you were kind of, like, expected to die  
25 within two or three years. And you kind of thought:

34

1 well, if I am going to die, I kind of, like, don't  
2 really want to expose, let's say -- I'm quite  
3 altruistic, really. If people are going to start to  
4 kind of, like, train me and put money into kind of,  
5 like -- you know, train me for a profession and  
6 suddenly I die on them, I kind of, like, think that  
7 that was not really worthwhile -- for them.

8 And additionally, there would have been kind of  
9 stress involved. You know, I was having days where at  
10 that stage I wasn't brilliant. Obviously the  
11 haemophilia at that was being relatively well  
12 controlled but there were good days and there were bad  
13 days and I thought: I'm not altogether sure I am going  
14 to train as an actuary now. So deciding to go into  
15 education seemed, in some sense, a safer bet, to  
16 continue on with education, because that would be --  
17 the ball would be much more in my court. If I studied  
18 to do a PhD and I couldn't go in to do the research on  
19 a Monday, then, that's fine, I'll make up for it  
20 tomorrow, type scenario. But having this regular kind  
21 of going in to work 9 o'clock in the morning,  
22 5 o'clock in the afternoon, that was something that I  
23 thought I would not be able to do.

24 So HIV was already, in some sense, beginning to  
25 affect my life choices. You know, from which

35

1 university I went to. Certainly at Treloar's there  
2 were lots of people who thought I would go to Oxbridge  
3 but, again, you know, the pressure and the additional  
4 stress, and the fact that if I got ill my parents  
5 would want to come and see me. So that kind of  
6 dictated which university I went to, and HIV also  
7 effectively dictated which profession I kind of, like,  
8 went into.

9 **Q.** So you obtained your PhD?

10 **A.** I did.

11 **Q.** And you stayed in academia for a number of years?

12 **A.** Yes.

13 **Q.** I think you have described that that choice was about  
14 the flexibility that it gave you?

15 **A.** Yes, academia in some sense, you know, is a land of  
16 kooks, really. You know, if you're an oddball in  
17 academia no-one really bats an eyelid. If you're not  
18 in for a day or two days, no-one bats an eyelid and,  
19 effectively, if you're working for yourself on  
20 a research project -- because I've said, if you miss  
21 a day, you catch up the following day or you set the  
22 computer programme to run overnight and come back  
23 two days later and see what results you've got.

24 **Q.** In terms of your personal relationships, what effect  
25 did your infections on, on having personal

36

1 relationships?  
 2 **A.** That's a very interesting question. I was quite late  
 3 to kind of find myself, sexually, really. And I think  
 4 perhaps HIV may have been kind of, in some cases, to  
 5 blame about that, because you're 15 years old, you're  
 6 just kind of working your way out, and then all of  
 7 a sudden you -- crikey, you've got this kind of, you  
 8 know, life-threatening disease, so you don't begin to  
 9 think about it, and so you put it off and you live  
 10 a bit longer, and so on and so forth.  
 11 But when it actually came to relationships, that  
 12 was really quite challenging for me as an individual,  
 13 because in some sense we, as haemophiliacs who'd been  
 14 infected in '84 and '85, had been conditioned to lie,  
 15 by the social environment at the time. And I'm sure  
 16 most people in this room, if I say the word "iceberg"  
 17 they'll know exactly what I'm talking about.  
 18 So the hysteria that the Government created  
 19 and -- basically meant that we were ostracised. And  
 20 it didn't really seem right, really. If you look at  
 21 kind of what's happening in Covid today and what  
 22 happened then, you know, people with it today get  
 23 a lot of, kind of, like, help and protection and their  
 24 families are looked after and you're given financial  
 25 assistance, and this and that and the other. Whereas

37

1 and made a lot more sense. And in some sense, for me  
 2 personally, that meant that it was much easier,  
 3 because I was looking for a partner in a group of  
 4 people who had experienced very, very similar things  
 5 to the haemophiliacs. You know, the gay community had  
 6 got absolutely -- forgive the pun -- bashed in the  
 7 nineties.  
 8 So in some sense, HIV was not so much of  
 9 a problem, really. So I'm very lucky to have found  
 10 a partner who kind of puts up with my mental health  
 11 issues and my, you know, the -- all the issues that  
 12 I've parked for 25 years ago that suddenly have  
 13 mounted up, and so on and so forth.  
 14 **Q.** And what can you tell us about your health until  
 15 about 2000? Then we'll pick up what's happened since  
 16 then.  
 17 **A.** Generally quite good. I was very fortunate in that  
 18 I didn't have any kind of AIDS related diseases or  
 19 symptoms apart from very minor things like shingles  
 20 and some kind of rash on my skin, which was very, you  
 21 know, pro-HIV or indicative.  
 22 I seem to remember at the time I was quite late  
 23 in starting AZT. The protocol at the time was to wait  
 24 until your CD4 count dropped below 200 before  
 25 starting. So I was quite late starting that, I think.

39

1 in 1985 you were basically ignored. Your voices were  
 2 not heard.  
 3 And when that came to relationships, that caused  
 4 a massive problem in trust. Balancing that trust.  
 5 I mean, if I started, you know -- thought about dating  
 6 you, for example, in 19 -- let's say -- 95, when do  
 7 I disclose my HIV status? If I disclose it on the  
 8 first date you're going to think, "Oh my god, I might  
 9 never see you again". Alternatively, if I wait a bit,  
 10 your response might be, "Do you not trust me? Why  
 11 didn't you tell me before?" So it was a very kind of  
 12 like very difficult kind of balance.  
 13 And the stigma associated with it was very  
 14 challenging. And I think the stigma associated with  
 15 the iceberg and the Government's, you know, response  
 16 to it in 1985 was such that the people who actually  
 17 wanted to say something couldn't because they'd been  
 18 scared into silence. You know, they didn't really  
 19 have a voice when it came to compensation or anything  
 20 like that. Because society meant that they would be  
 21 badly, kind of, affected or, you know, subject to  
 22 discrimination.  
 23 So it wasn't effectively until I, you know,  
 24 I finally discovered that I, kind of, like, preferred  
 25 boys rather than girls, that everything kind of fitted

38

1 And you were given additional things like Septrin for  
 2 pneumonia which was a risk, which was probably, you  
 3 know, one of the big side effects and then, you know,  
 4 the drugs obviously created huge side effects, the AZT  
 5 and the Stavudine causing the lipodystrophy and the  
 6 current problems with fats and the way they're  
 7 distributed in the body and how much cake you can eat  
 8 and all things like that.  
 9 So up until about 2000 I would say I was  
 10 reasonably kind of like okay. And then unfortunately  
 11 of course the hepatitis started to become a bit more  
 12 of an issue. And I don't know what it was like for  
 13 other people but hepatitis was much more insidious,  
 14 really, because you felt kind of 99.99% as well as you  
 15 did yesterday, and it's only after several years that  
 16 those 0.01% start to built up and it's not until you  
 17 think, "Actually, how far have I fallen down here?"  
 18 And you look up and think, "Oh crikey, I'm quite  
 19 a long way down".  
 20 So it had gotten to the stage where Cardiff were  
 21 considering doing, kind of, liver biopsies for  
 22 cirrhosis and things like that and they then decided  
 23 to have a go with the interferon in about 2000, 2001.  
 24 **Q.** You underwent a treatment with interferon, ribavirin?  
 25 **A.** Yes.

40

1 **Q.** And you think a third drug was added in?  
 2 **A.** I think I was on a trial for a third drug and I seem  
 3 to remember it being called amantadine, which was kind  
 4 of like an anti-flu drug and they were seeing if that  
 5 had any kind of effect at all. I had an amenable  
 6 genotype, I think was the word, which meant the  
 7 hepatitis was -- it was a good or high probability  
 8 of it being cured or shifted.  
 9 **Q.** But in that first round of treatment you didn't clear  
 10 the virus?  
 11 **A.** Correct. I did not.  
 12 **Q.** So what was your response to that? What did you then  
 13 do?  
 14 **A.** I think, looking back on it, that's when things  
 15 started to go south in a kind of mental kind of way,  
 16 really. After the interferon and, I'm sure, due to  
 17 the increase in hepatitis, I was not in a brain fog  
 18 all the time but I didn't quite have the mental  
 19 capacity that I did used to have. And that, kind of,  
 20 like, was a worry, really. And so you are back to,  
 21 kind of, like, thinking, "Okay, I've got another  
 22 two years to go". It's almost like having a loyalty  
 23 card with death, you know, have five close encounters  
 24 and get the ultimate one for free type scenario, do  
 25 you know what I mean?

41

1 like injection days, but after that I was generally  
 2 okay. You know, I'd have to possibly take it quiet  
 3 for -- imagine having a Covid vaccination, that type  
 4 of thing these days.  
 5 For the second batch of treatment, the  
 6 interferon, the pegylated interferon, the side  
 7 effects -- the physical side effects were much better  
 8 because it was effectively a slow release substance,  
 9 you didn't get these huge spikes in concentration of  
 10 the drug that the body had trouble handling and  
 11 therefore reacted to. So consequently it was much  
 12 more physically easier to handle. The only problem  
 13 is, of course, the active ingredient is in your body  
 14 for longer so, as a result, it's doing its thing for  
 15 longer, so I was borderline kind of neutropenic, so my  
 16 white blood cells were really getting quite hammered  
 17 and bashed, really. But we managed to avoid any kind  
 18 of additional transfusions of white --  
 19 **Q.** Needing platelet --  
 20 **A.** Yeah.  
 21 **Q.** You didn't need anything like platelets --  
 22 **A.** No.  
 23 **Q.** -- any additional blood support?  
 24 **A.** Correct, yes.  
 25 **Q.** In terms of your physical -- sorry, I should say that

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1 So it was kind of, "Oh well, okay, well, we've  
 2 lasted a decade longer than an awful lot of people, so  
 3 that was a pretty good show, so let's kind of carry  
 4 on."

5 So I basically thought, well, if I've only got  
 6 a year or two to go, may as well make the most of it.  
 7 So I kind of didn't take on another research project  
 8 and went round the world for a year. I thought,  
 9 "Right, well, this is it". And Cardiff wanted six  
 10 months, I wanted a year. They wanted nine months,  
 11 I said, "Oh" -- they wanted eight months, I said, "Can  
 12 we go for nine?" And so that was it really.

13 **Q.** And when you returned to the UK you then had further  
 14 treatment with pegylated interferon and ribavirin?

15 **A.** Correct, yes.

16 **Q.** And what can you tell us about that? The side effects  
 17 of it and --

18 **A.** The side effects, so going back to Dr Dasani from  
 19 a previous conversation, around about this time also  
 20 we were starting to do some kind of tours around the  
 21 country with another individual, who also went through  
 22 similar treatments to me.

23 Now, on his first go of interferon, he could not  
 24 get out of bed for six months. And cleared it.  
 25 I alternatively yes, I felt a bit rough, on kind of

42

1 treatment cleared your --

2 **A.** Yes, it did.

3 **Q.** -- hepatitis C at that point?

4 **A.** Yes, it did.

5 **Q.** In terms of your physical health since that treatment,  
 6 what's your physical health been like?

7 **A.** I would say generally pretty stable. But as in with  
 8 most haemophiliacs, a gradual decline in kind of  
 9 mobility and joint functions and so on and so forth  
 10 like that.

11 **Q.** And I think you have described that you feel like  
 12 you're mentally less sharp than you used to be?

13 **A.** Yes. I mean, when I came back from my round the world  
 14 trip, really, I thought I just cannot do academia  
 15 anymore. I just cannot. And that made finding  
 16 employment really quite challenging because, you know,  
 17 the avenue of what I'd really always wanted to do, you  
 18 know, to become an actuary -- because numbers were  
 19 meat and drink to me. I could -- they just talked to  
 20 me like -- you know, it was easy.

21 And so academic, yes, I would have been  
 22 a passible academic but I wasn't going to, you know,  
 23 rewrite the world. And with the mental fog and the  
 24 depression that effectively started then -- and we all  
 25 probably have some insight into depression, about how

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1 it's an ever kind of diminishing circle, that you feel  
 2 unhappy so you feel more depressed, and some people  
 3 turn to props, shall we say, to help them. I never  
 4 really felt the need to do that. But actually, it was  
 5 a long time before I actually admitted that mental  
 6 health was an issue, and that I was really starting to  
 7 struggle then. You know, that stoic mentality: don't  
 8 talk to anybody about this type of thing.

9 **Q.** You described earlier that you'd parked a lot --  
 10 **A.** Yes.  
 11 **Q.** -- about what had happened?  
 12 **A.** Yes.  
 13 **Q.** And I think in your statement you talk -- that that's  
 14 really come back to impact you in your mental health  
 15 now?  
 16 **A.** Yes, definitely.  
 17 **Q.** What can you tell us about that?  
 18 **A.** So obviously things that you had parked, that you  
 19 never really gave credence for, so for example,  
 20 something that I really wondered whether it actually  
 21 existed, is survivor guilt. You know, why me? Why  
 22 was I the lucky one that in some sense survived  
 23 whereas -- and I could name, you know, 20 names here  
 24 that didn't. That doesn't kind of like -- you know,  
 25 why? So that obviously was an issue. I think

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1 And of course, that all adds into the self --  
 2 you know, the lack of self-worth and -- should I  
 3 really be here? And what's the point of it all? And  
 4 things like that, really.

5 **Q.** I want to pick up a final topic with you. It's  
 6 related. I just want to talk with you a little bit  
 7 about your interactions with the trusts and schemes.  
 8 **A.** Mm-hm.  
 9 **Q.** You received payments through the Macfarlane Trust and  
 10 from the Skipton Fund.  
 11 **A.** Yes.  
 12 **Q.** What was your experience of dealing with the  
 13 Macfarlane Trust?  
 14 **A.** I'm going to put my statistical head on here for  
 15 a moment. And I'm absolutely sure that you will have  
 16 heard a lot of testimony about the Macfarlane Trust  
 17 and about The Haemophilia Society. And as part of  
 18 statistics, one of your jobs is to do what's called  
 19 a meta analysis. In other words, take all of the  
 20 available data and take a step backwards and try to  
 21 see the whole picture, really. And I think it's only  
 22 human that you get annoyed at the public face of the  
 23 company.  
 24 So if your train is late or, you know, the  
 25 barrier is shut, you start having a go at the poor old

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1 obviously the diagnosis of HIV, the unfairness of it.  
 2 And in some sense I think I'm -- at the way we were  
 3 treated, really, in the eighties. This, you know,  
 4 ostracisation of us. That really wasn't fair, and  
 5 very, very inhumane, really. So all of these issues  
 6 started to come up. Along with, you know, a sense of  
 7 worthlessness, a sense of, you know, you really  
 8 feeling that you could have contributed to society in  
 9 some way instead of just sitting at home trying to  
 10 shoot zombies on the PlayStation.

11 So that's been a real challenge for me,  
 12 particularly somebody with an active -- you know,  
 13 hyperactive mind who just thinks all the time or tries  
 14 to think all the time and achieves nothing.

15 **Q.** Because in terms of work, since you've had the  
 16 hepatitis C treatment --  
 17 **A.** Yes.  
 18 **Q.** -- and the depression --  
 19 **A.** Yes.  
 20 **Q.** -- have you been able to work in any --  
 21 **A.** Not really, no. I have tried occasionally, but --  
 22 again, a friend had a finance company, I tried to work  
 23 for him, and I just couldn't. I just didn't have  
 24 any -- I couldn't write the computer programs.  
 25 Couldn't kind of do things like that.

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1 lady at the ticket barrier. And it's not her fault  
 2 that you were 30 seconds late, but that's who you rant  
 3 at. You know, if your router fails and you ring up  
 4 and are kept on this endless kind of mindless  
 5 telephone system for hours before you actually get to  
 6 somebody, it's not their fault. What you really want  
 7 to do is you want to complain to somebody a bit higher  
 8 up and say, "Look, you need to get your system sorted  
 9 out."

10 So trying to take a step backwards and trying to  
 11 kind of see a bigger picture, like everyone else, my  
 12 experience with the Macfarlane Trust was not great.  
 13 And it has caused (a) a lot of mental health issues  
 14 and (b) a lot of annoyance. So the other half rolls  
 15 his eyes, for example, if I mention the Macfarlane  
 16 Trust, "Oh god, he's going on his hobby-horse again,  
 17 shut him up for god's sake."  
 18 But if I was to take a step backwards I think  
 19 what I would say is that, fundamentally, I think the  
 20 Macfarlane Trust was set up incorrectly. It was set  
 21 up incorrectly by the Government. And I think it  
 22 ended up that we were just kind of -- we became  
 23 reliant on them, in some sense, to survive. We had to  
 24 be almost subservient to them. In order to survive,  
 25 we had to, you know, kind of go begging for money and

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1 this that and the other. And that does not seem right  
2 to me for a charitable organisation.

3 Now whether the Government kind of deliberately  
4 did that or not is open to question that others will  
5 have to answer. But the Government, you know, never  
6 accepted any responsibility for what happened. The  
7 fact that they allowed dirty blood products into the  
8 country, and then, when people were affected, they  
9 effectively ostracised them and gave them very little  
10 or no help at all. And all of a sudden, here is an  
11 organisation set up as the front piece of the  
12 Government, and we should be grateful to them. That  
13 seems very odd to me. So, again, whether it was by  
14 intention or whether that's the way that it just  
15 panned out, I don't know.

16 To do something probably that's going to be  
17 quite unpopular with the haemophiliacs in the room,  
18 I just want to take the Macfarlane Trust's side for  
19 just minute because it had a pretty big heavyweight in  
20 the opposite corner: the British Government at the  
21 time. The Thatcher Government at the time, or the  
22 remnants of the Thatcher Government at the time, that  
23 many people -- regardless of what you thought of their  
24 policies, as far as a well-run Government was  
25 concerned, managed to do things. It was pretty good.

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1 a five-hour discourse.

2 **Q.** Mr BC, they're the questions I have for you. I'm just  
3 going to turn and see if there is anything else.

4 There's nothing further from behind me.

5 Questions from SIR BRIAN LANGSTAFF

6 **SIR BRIAN LANGSTAFF:** Well, you've described yourself as  
7 having an active, hyperactive mind, worked in  
8 academia, and a desire to see the whole picture. What  
9 do you, reflecting -- as you obviously do -- on  
10 everything that has happened, and trying to see why  
11 and how it happened, what would you say were the  
12 principal reasons that you suffered from HIV infection  
13 and hepatitis C infection?

14 **A.** It's a difficult question because obviously you don't  
15 know the facts. But I think that the Government in  
16 '83 and '84 should have been a lot more proactive.  
17 They should have protected us a lot more than they  
18 did.

19 I think -- without any evidence, I think they  
20 knew that this blood caused some problems. And they  
21 didn't act quickly enough to stop it. Why? That's an  
22 interesting question. And one that I do not have an  
23 answer for. Whether it was ignorance, whether it was  
24 financial, whether it was -- I'm going to be really  
25 harsh here, and this is outside the remit of the

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1 It did what it -- you know, it did what it said on the  
2 tin, really.

3 So given the fact that they and the Haemophilia  
4 Centre had such an overwhelming opponent, you now have  
5 to make a call as to your way forwards. What do you  
6 do to try to benefit the people the most that you're  
7 trying to represent, against, effectively, a massive  
8 steamroller?

9 So it was -- and I could wax lyrical about, you  
10 know, the unfairness, the postcode lottery, why were  
11 people in this postcode paid more than people in that  
12 postcode? I could go on until the cows come home.  
13 But ultimately I just feel a lot of anger and you want  
14 to feel it towards the Macfarlane Trust and you want  
15 to feel it towards, in some sense, The Haemophilia  
16 Society, for not representing you well enough, but,  
17 you know, actually, as I think about it more, with my  
18 brain fog, I kind of, like, you know, blame the  
19 Government increasingly more for setting up this  
20 completely bonkers scheme, let's be honest, that just  
21 made little sense.

22 They kind of -- the Government failed to protect  
23 us against HIV, and then failed to respond when we got  
24 it and wanted help with it. So that's what I would  
25 say about the Macfarlane Trust, without going into

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1 Inquiry -- but whether it was because it was only the  
2 bleeders and the queers who were being infected, so it  
3 didn't really matter. If it had been the general  
4 population, for a disease that was affecting the  
5 general population, would their actions have been the  
6 same? I don't honestly know.

7 **SIR BRIAN LANGSTAFF:** Thank you.

8 Can you think of anything that, in terms more  
9 closely related to your treatment -- although you  
10 answered the question I asked you -- that you would  
11 have done differently? Even within the scope of the  
12 Government's failures, as you've expressed them.

13 **A.** I think, having had the experience of having had  
14 a decade where I had no treatment at all, I am  
15 certainly not unique but I -- you know, I'm quite rare  
16 in knowing what not having Factor VIII felt like. So  
17 if I had been told, "Look, if we carried on giving you  
18 this treatment, it has these risks associated with it.  
19 What would you like us to do?" I could quite imagine  
20 myself at the day saying, "I don't want to take that  
21 risk at this precise moment in time". I would go back  
22 to not having any treatment at all.

23 In -- obviously in 1983, there were effectively  
24 back-up treatments for me, that in some sense were  
25 considered safer than the Armour product that I was

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1 being hammered with. So there could have been  
2 a compromise to say, right, I don't want the Armour  
3 product any more but I might take the FEIBA, because  
4 that's a European product and that in some sense is  
5 cleaner.

6 So like everything, knowledge is power, isn't  
7 it? It empowers the individual to make a choice. And  
8 I felt that we never really had that information. We  
9 were never given it, and so that choice effectively  
10 was taken away from us.

11 **SIR BRIAN LANGSTAFF:** Thank you very much for that.

12 **MS FRASER BUTLIN:** I've been asked to raise a question  
13 from another legal representative.

14 **A.** Absolutely.

15 **Q.** When did you first become aware of your T-cell values  
16 and why they were being recorded?

17 **A.** I cannot give an honest answer to that, or an accurate  
18 answer to that, I should say. I'll give you an honest  
19 one. I would say, as a guess, I was not aware of my T  
20 cells being important in Treloar's, so it would have  
21 been after I left Treloar's, so that would have been  
22 back under Cardiff's regimen, I would think. So that  
23 would have been probably somewhere in the region of  
24 1990.

25 **Q.** Is there anything else you would like to add?

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1 **A.** Exactly. It's very odd the way the brain works, isn't  
2 it? And I would just like to thank the Inquiry,  
3 really, for a decade of -- or sorry, no, for like  
4 30 years of people not really being interested in what  
5 we have to say. It is quite enlightening and  
6 empowering to be in a room with people who actually  
7 are interested in what we have to say. And obviously  
8 the more information, the more different stories you  
9 get, you will build up a picture, and for some people  
10 it's mental health issues, for other people it's  
11 personal loss. And of course it's all very, very  
12 individual stories.

13 On a personal level, I think, you know,  
14 gradually things are improving. I'm not mentally  
15 grading sharp objects on a scale of one to ten  
16 anymore, shall we say? So that's definitely an  
17 improvement. But thank you and thank you very much  
18 all for listening.

19 **SIR BRIAN LANGSTAFF:** Thank you.

20 [Applause]

21 Well, we'll take a break until 11.55. 11.55.

22 **(11.24 am)**

**(A short break)**

24 **(11.55 am)**

**(Proceedings delayed)**

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1 **A.** I don't think so. I think I've hopefully explained  
2 everything as best as I possibly can through the brain  
3 fog but there we go. Thank you.

4 **SIR BRIAN LANGSTAFF:** I have to say, the brain fog is not  
5 apparent.

6 **A.** Thank you.

7 **SIR BRIAN LANGSTAFF:** Nor is, in particular -- but perhaps  
8 this is because of the practice that you've had -- is  
9 the iceberg particularly obvious. You may have shown  
10 us some of what's beneath the surface.

11 **A.** Yes.

12 **SIR BRIAN LANGSTAFF:** And I'd just like to thank you for  
13 that.

14 **A.** Thank you very much.

15 **SIR BRIAN LANGSTAFF:** And for what is again different,  
16 individual approaches, the value of listening to  
17 different witnesses, the different backgrounds, we  
18 take a rather more reflective view born of academia  
19 and you're interested in statistics than others might.  
20 You've spoken in particular very powerfully about the  
21 stigma and the problems that have come mentally with  
22 coming to terms with what you've had to face.

23 And unusually, perhaps, you can't precisely  
24 recall the conversations in which you heard the  
25 dreaded news.

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1 **(12.03 pm)**

2 **SIR BRIAN LANGSTAFF:** Well, Lee, I'm sorry to have kept  
3 you waiting just a few minutes. There was something  
4 which had to be done before your evidence began but  
5 now you're here. You'd like to be known as Lee,  
6 I gather?

7 **A.** Yeah, that's fine, yeah.

8 **SIR BRIAN LANGSTAFF:** Mary will ask you to take the oath.

9 **A.** Okay, thank you.

**LEE STAY (affirmed)**

**Questioned by MS RICHARDS**

12 **MS RICHARDS:** Lee, you were born with severe  
13 haemophilia A?

14 **A.** That's correct.

15 **Q.** And it was diagnosed when you were a baby?

16 **A.** Mm-hm.

17 **Q.** And your understanding is you were treated at  
18 St George's Hospital in London, and then at the  
19 Ashford Hospital in the early seventies with  
20 cryoprecipitate?

21 **A.** That's right, yeah.

22 **Q.** Now, in 1975 I think you transferred to the  
23 Hammersmith Hospital?

24 **A.** Yeah, I did.

25 **Q.** And you were under the care there of Dr Mibashan?

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- 1 A. Mm-hm.  
 2 Q. And that's where you first received factor  
 3 concentrates?  
 4 A. Yes.  
 5 Q. Soumik, could we please have WITN1541003.  
 6 If we go to the next page, these are some  
 7 records you've exhibited from the Hammersmith Hospital  
 8 from 1975, and you're about 7 years old at this point,  
 9 I think?  
 10 A. Yeah.  
 11 Q. And we can see, top left-hand corner, just zoom in on  
 12 the handwriting there, please. There's a reference  
 13 there "Received", I think that's what the abbreviation  
 14 is, "28.8.76 from Dr Craske".  
 15 Did you know anything about any participation in  
 16 any research or studies or investigations involving  
 17 Dr Craske?  
 18 A. Not at all, no.  
 19 Q. And it's only many years later you've learnt that  
 20 Dr Craske was at the Public Health Laboratory Service?  
 21 A. That's right, yeah.  
 22 Q. And then if we go back to the page, and we just see  
 23 the whole page, we can see -- sorry, top of the page  
 24 refers to "Hemofil Records", and then we can see your  
 25 name.

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- 1 A. Mm-hm.  
 2 Q. Various dates. We don't need to look at the precise  
 3 dates. But you're being given Hemofil on various  
 4 occasions at the Hammersmith Hospital in 1975?  
 5 A. Yeah.  
 6 Q. And if we go to the next page, we can see, top of the  
 7 page, these are equivalent records but for Kryobulin?  
 8 A. Mm-hm.  
 9 Q. So you're given a second type of commercial  
 10 concentrate in '75, age 7 or thereabouts --  
 11 A. Yeah.  
 12 Q. -- at the Hammersmith Hospital?  
 13 A. Yeah.  
 14 Q. And I think if we go over the page, this is an extract  
 15 from the Hammersmith's annual returns from 1975, and  
 16 if we go to the bottom of the page, we can see  
 17 reference to you there. There's reference to a  
 18 "[clinical] response to [Factor] VIII", and then  
 19 a reference to "Virology records not found". That's  
 20 in relation to jaundice.  
 21 A. Mm-hm.  
 22 Q. Or hepatitis B. Do you know anything about what those  
 23 virology records were?  
 24 A. No idea.  
 25 Q. Now we can take that down, thank you.

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- 1 You moved on to receiving home treatment in  
 2 1976.  
 3 A. Yes.  
 4 Q. So that was administered by your parents?  
 5 A. Mm-hm, yeah, my father.  
 6 Q. And your understanding is you received Hemofil,  
 7 Kryobulin, and Lister --  
 8 A. Mm-hm.  
 9 Q. -- products. And then, from March 1978, Factor VIII?  
 10 A. Yeah.  
 11 Q. And we can probably pick that up most easily from  
 12 WITN1541004, please.  
 13 If we go to the second page to start with, we  
 14 can see this is an extract from your records from the  
 15 National Haemophilia Database maintained by UKHCDO.  
 16 A. Mm-hm.  
 17 Q. And if we go to page 4, it's in reverse chronological  
 18 order so let's pick it up at the bottom of the page.  
 19 We've got a reference, 1970, to you receiving cryo at  
 20 St George's. And then we can see for 1975 and '76,  
 21 when you're under the care of the Hammersmith  
 22 Hospital, there are four entries which refer to  
 23 "Dr Craske's research work". Did you know anything  
 24 about that until you saw these records?  
 25 A. Not at all. I had no idea.

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- 1 Q. And is this right, you still don't know what that's  
 2 a reference to?  
 3 A. No, nobody can seem to tell me, you know, why they're  
 4 like that.  
 5 Q. And we can see, on the right-hand side, this, under  
 6 the heading of "Dr Craske's research work", appears to  
 7 show you receiving Hemofil and Kryobulin --  
 8 A. Mm-hm.  
 9 Q. -- in the course of those years.  
 10 Yeah, I mean, that would match the other records  
 11 you just showed.  
 12 Q. Sorry, can you just speak slightly closer into the  
 13 microphone?  
 14 A. Yeah, sure.  
 15 Q. Thank you.  
 16 Then if we go up the page we can see the next  
 17 few entries for the Hammersmith Hospital, so this is  
 18 in the late seventies, we can see you getting  
 19 Lister -- the Lister product, BPL product,  
 20 Factor VIII, and also Factorate, the Armour product?  
 21 A. Yeah.  
 22 Q. We can take that down because we will look at what you  
 23 got at Treloar's from some other records.  
 24 Just before we come to Treloar's, as far as  
 25 you're aware, were your parents given any information

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1 by the Hammersmith Hospital about any risks associated  
 2 with the use of factor concentrates?  
 3 **A.** Not that I'm aware of, no.  
 4 **Q.** Now you went to Treloar's starting in September 1980?  
 5 **A.** Mm-hm.  
 6 **Q.** How did that come about?  
 7 **A.** Um, I went to a normal infant and junior school but,  
 8 when it came to deciding what secondary school to go  
 9 to, the Local Education Authority, as I understand it,  
 10 refused to allow me to go to a comprehensive school,  
 11 as they were known then. And it was then that --  
 12 suggested I went to Treloar's. So that's how the  
 13 process came about.  
 14 **Q.** And do you know what the education authority's concern  
 15 was? Was it that you would miss too much school?  
 16 **A.** No, it wasn't that, because I didn't actually miss  
 17 that much schooling during that, you know, infant and  
 18 junior period. I think it was more the risks to me  
 19 being hurt -- you know, because I was never allowed to  
 20 out to play and things like that. I always had to,  
 21 like, stay in the library when I was in juniors and so  
 22 on. But I think it was more the risks of me being  
 23 hurt and having bleeds and that caused by, you know,  
 24 people hitting me or just running into me and things  
 25 like that.

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1 and then you had, like, a consulting room, I believe,  
 2 on one side, then you had the treatment room on the  
 3 other. After 1981 they built an extension to that  
 4 and, you know, it was much bigger and they had  
 5 the laboratory and other things on site.  
 6 But yeah, generally, as I say, after your  
 7 initial bleed you would then be reviewed potentially  
 8 mornings and evenings, you know, just for review of  
 9 joints, and if you needed any further treatment and so  
 10 on, and that would go on obviously until the bleed had  
 11 recovered.  
 12 **Q.** You mentioned in your statement that there would often  
 13 be a lot of blood tests?  
 14 **A.** Yeah.  
 15 **Q.** Were you ever told what those blood tests were for?  
 16 **A.** Very rarely. The only ones that I recall distinctly  
 17 were the so-called pre and post-blood tests that we  
 18 used to have.  
 19 So you used to have a blood test before having  
 20 a dose of Factor VIII and then about 20 minutes later  
 21 they'd give you another blood test to see how that had  
 22 affected the -- raised the Factor VIII levels in the  
 23 blood.  
 24 **Q.** And then you moved to the upper school.  
 25 **A.** Yeah.

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1 **Q.** But you spent the first three years or so in the lower  
 2 school. Before I ask you anything about the details  
 3 of your treatment for your haemophilia there, what was  
 4 your impression of Treloar's when you arrived and  
 5 during those first years at the lower school?  
 6 **A.** Um, well, it was -- it seemed very big at the time,  
 7 because, you know, I'd never been to a boarding school  
 8 before. It seemed very good. The impression that I  
 9 got was that, you know, it was a very good place to be  
 10 and obviously with the facilities for treating  
 11 haemophiliacs on site, you know, I felt that it was  
 12 going to be a big advantage to me.  
 13 **Q.** And you described that when you were at the lower  
 14 school, you'd be taken by van to the Haemophilia  
 15 Centre in the upper school for treatment?  
 16 **A.** Yeah, that's right.  
 17 **Q.** And again, you talked about there being regular  
 18 clinics there. What can you recall about how and when  
 19 you would turn up at the Haemophilia Centre in the  
 20 upper school?  
 21 **A.** Well, obviously when you got a bleed, you would go to  
 22 the sick bay at the lower school and then they would  
 23 radio for a van to take me to the upper school for  
 24 treatment. You know, initially the treatment area  
 25 was -- it was, like, one corridor, one long corridor,

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1 **Q.** And then your treatment effectively was on site  
 2 because the Haemophilia Centre was located in the  
 3 upper school?  
 4 **A.** That's right, yeah.  
 5 **Q.** And did the treatment arrangements work in pretty much  
 6 the same way?  
 7 **A.** Yeah, yeah, there was still the morning and evening  
 8 clinics. It just obviously meant that you'd just walk  
 9 over there rather than having to get transport.  
 10 **Q.** You were taught to self-administer factor concentrates  
 11 at Treloar's.  
 12 **A.** Mm-hm.  
 13 **Q.** How would you go about that when you had a bleed and  
 14 you were going to self-administer? Can you talk us  
 15 through the process and how you'd get the product and  
 16 how you'd make it up and know which product to use.  
 17 **A.** Yeah. Well, first of all, you see the doctor, who  
 18 would obviously do the initial evaluation, and he  
 19 would then prescribe a percentage dose on the sheet  
 20 and you'd take that sheet down to the treatment room.  
 21 I'd then -- I would self-administer it, then I'd --  
 22 you know, I'd need to calculate how much Factor VIII  
 23 I'd need to give myself. And that was done by means  
 24 of a graph. So along the bottom of the graph you had  
 25 your weight, and then there was kind of lines going up

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1 showing what the percentage -- each percentage, so if  
2 it was a 10% dose, 20% dose, 30% dose, and then you'd  
3 read across and that would give you how many units  
4 you'd have to give that particular percentage. And  
5 then you'd try and get treatment that would be as  
6 close as possible to that number of units that you  
7 read off.

8 **Q.** And where would you actually get the bottles of  
9 concentrate from? Was there a fridge or did someone  
10 give it to you?

11 **A.** Most of the time I think somebody gave it to you.  
12 I seem to recall, I think I may have actually got it  
13 from the fridge myself occasionally. That may have  
14 been right at the end of, you know, the period I was  
15 there, but the methodology was to get to as close to  
16 that dose -- that particular number of units as  
17 possible, and that may involve using more than one  
18 batch, because, you know, you might have -- if you  
19 needed, like, 1,200 units you might have one of 500  
20 units and one of 200 units. So though they didn't mix  
21 product, they did mix batches.

22 **Q.** So for a single treatment you wouldn't have, say,  
23 Factorate and Kryobulin mixed together?

24 **A.** No.

25 **Q.** But you might have, if you were having treatment with

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1 If we look first of all at TREL0000267\_053,  
2 please, Soumik.

3 This is something called a "Pupil Review Sheet  
4 ... Medical", and it's one of a number of them in your  
5 records, and I think we've seen a very similar  
6 document in relation to another witness. We can see  
7 it identifies:

8 "Disability: Haemophilia

9 "Number of visits since last review, as  
10 outpatient ..."

11 Someone has recorded "Many, for treatment",  
12 a staff member, presumably. And then if we go down  
13 the page we just see the question there:

14 "Parental involvement in medical care: Yes."

15 Now that is obviously right in the sense that  
16 when you were at home, your parents were very closely  
17 involved with your medical care; is that right?

18 **A.** That's right, yeah.

19 **Q.** But when you were at Treloar's, did they have any  
20 involvement?

21 **A.** No, none at all.

22 **Q.** And we can just note the date on this is  
23 23 November 1983. If we then look at TREL0000267\_054,  
24 please. This is a form -- and again, there are  
25 a number of copies or versions of this form, different

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1 Factorate on that occasion, more than one batch of  
2 Factorate to make it up to the right number of units?

3 **A.** Yes.

4 **Q.** Were you told anything at Treloar's about any risks  
5 associated with the use of factor concentrates?

6 **A.** No.

7 **Q.** And as far as you're aware, were your parents ever  
8 told by Treloar's of any such risks?

9 **A.** No. Not that I'm aware of.

10 **Q.** As far as you know, to what extent was there any  
11 interaction between Treloar's and your parents?

12 **A.** As far as I can tell, very little. You know,  
13 basically my parents just relied on what I told them.  
14 They were never given a record of what bleeds I had,  
15 what treatments I had, what blood tests I had. To my  
16 knowledge, they had nothing.

17 **Q.** I think there's one little medical report we've seen  
18 with another witness, and we'll look at a sample in  
19 your records.

20 **A.** Yes.

21 **Q.** And that's all you can recall of --

22 **A.** That was the only thing, yeah.

23 **Q.** And then, just on the theme of parental involvement,  
24 there's a couple of documents I want to ask you to  
25 look at.

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1 dates, in your Treloar's records, Lee, but it looks  
2 like your parents were expected to provide information  
3 to the school. And we'll just have a look at this:

4 "Lord Mayor Treloar College.

5 "To: All Parents:

6 "This form must be completed and returned to  
7 Sick Bay on the first day of next term."

8 And then we can see it doesn't appear to be  
9 specific to haemophilia pupils, so:

10 "Has your son ... had any illness during the  
11 holiday? If so, please give details.

12 "Has he/she been in contact with the any  
13 infectious illness? If so, please contact Sick Bay  
14 before returning to School.

15 "Has he/she attended an outpatient appointment  
16 at any Hospital in the holiday? If yes, please give  
17 date, Consultant's name, Hospital address and reason  
18 for visit."

19 And we can see some details filled in there of  
20 you going to the Hammersmith during that particular  
21 holiday.

22 Then:

23 "Has he/she been seen by:

24 "A) Doctor

25 "B) Dentist

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1 "C) Optician  
 2 "Have there been any all alterations in his/her  
 3 drugs or treatment during the holiday?  
 4 "Are there any other points you would like to  
 5 add about his/her medical care?"  
 6 And your father or mother has recorded "Bleed  
 7 into left thigh".  
 8 Do you recall these forms?  
 9 **A.** I do remember them, yeah. I think they were sent out  
 10 during the holidays for them to be completed and  
 11 brought back at the beginning of each term. I'm not  
 12 sure whether it happened every time but I certainly do  
 13 remember number of them being filled in and taken  
 14 back, we took them back when we went back to school.  
 15 **Q.** So there's information going from your parents to  
 16 Treloar's --  
 17 **A.** Yeah.  
 18 **Q.** -- in relation to what has happened in the holidays?  
 19 **A.** Mm-hm.  
 20 **Q.** But as far as you're aware, no information going from  
 21 Treloar's to your parents?  
 22 **A.** Correct.  
 23 **Q.** Can we go back then to WITN1541004.  
 24 And look again at page 4, this is the National  
 25 Haemophilia Database extract, and we can see various

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1 getting Hemofil?  
 2 **A.** Yeah.  
 3 **Q.** So pretty much straight away your first treatment or  
 4 one of your first treatments there is with Hemofil?  
 5 **A.** Yeah.  
 6 **Q.** If we go over the page we can see again, in the same  
 7 section of the form, that you're treated with Hemofil.  
 8 **A.** Yeah.  
 9 **Q.** If we go to the next page, this is November of 1980,  
 10 so again still your first term, it's not such quite  
 11 clear writing but I think that's the Interhem --  
 12 **A.** Mm-hm.  
 13 **Q.** -- that's been referred to there.  
 14 If we go to page 5, we've got a clearer entry  
 15 there for you being treated with Interhem, if we go  
 16 over to page 6 again we can see treatment with  
 17 Interhem?  
 18 **A.** Yes.  
 19 **Q.** If we go to page 7, again, this all still within your  
 20 first term, we can see treatment with Hemofil. If we  
 21 go to page 8, treatment with Interhem.  
 22 And then page 9, we're now into your second  
 23 term, January '81, treatment with Interhem.  
 24 If we go to page 11 -- and we don't have  
 25 records, I think, of every treatment in this format.

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1 references there to Hampshire Comprehensive Care  
 2 Centre. That is in fact referring to Treloar's, isn't  
 3 it?  
 4 **A.** Yes.  
 5 **Q.** And if we just look at -- by way of example, we can  
 6 see you getting there, if we look from the top of the  
 7 page down, even though it is in reverse date order, we  
 8 can see you getting Lister product, BPL product, and  
 9 Factorate commercial product in 1982.  
 10 **A.** Yeah.  
 11 **Q.** In 1981, at Hampshire, you're recorded there as  
 12 getting Hemofil, Factor VIII, Interhem, Kryobulin,  
 13 and, again Factorate and, similarly, in 1980 you're  
 14 recorded as getting Interhem and Hemofil.  
 15 **A.** Yeah.  
 16 **Q.** And then if we look at TREL0000253\_022, please,  
 17 Soumik.  
 18 These are some records from Treloar's which show  
 19 your treatment and if we see the first date is  
 20 12 October 1980. So is that within a few weeks of you  
 21 starting at Treloar's?  
 22 **A.** Yeah, it would be, yeah.  
 23 **Q.** If we look back down the page and we look on the  
 24 left-hand column halfway down the page, we have the  
 25 entry "Units Material", and we can see you're there

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1 We're now in late '82. We can see you've got the  
 2 Lister product recorded there, so the NHS product BPL.  
 3 And if we go over the page, we can see Lister  
 4 again, in December '82.  
 5 If we go to page 13, we can see Lister in  
 6 January '83.  
 7 And then if we go to page 15, we can see, this  
 8 is January '83, you're being treated with Kryobulin?  
 9 **A.** Yeah.  
 10 **Q.** Then if we go over the page, this is February '83,  
 11 treated with Factorate.  
 12 So a range of different commercial concentrates  
 13 and also, from time to time, the NHS concentrate?  
 14 **A.** Yeah, yeah.  
 15 **Q.** And was there ever any discussion with you about the  
 16 implications of different concentrates? Or whether  
 17 one posed a greater risk than others or anything of  
 18 that nature?  
 19 **A.** No, nothing at all. I'm not sure what they used for  
 20 their selection criteria but it was just what they had  
 21 at the time or whether there was any other reason for  
 22 giving particular product types. I don't know. But  
 23 there was certainly no discussion about, you know, the  
 24 effectiveness or not.  
 25 **Q.** Then if we look at WITN1541009, please, Soumik. It's

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1 the second page.  
 2 So we can see a form here, we've seen very  
 3 similar forms or identical forms, I think, for other  
 4 witnesses.  
 5 "Please complete and return to Dr Aronstam,  
 6 Lord Mayor Treloar Hospital, Alton, Hampshire.  
 7 "I ..."  
 8 And is that your dad's name there?  
 9 **A.** It is, yeah.  
 10 **Q.** "... agree to Lee Stay taking part in a trial as  
 11 explained by Dr Aronstam."  
 12 And signed, it would seem, by your father.  
 13 Do you know anything about what that trial was?  
 14 **A.** No, not at all.  
 15 **Q.** And like the other examples of this form we've seen  
 16 for other pupils, it's undated.  
 17 **A.** Yeah.  
 18 **Q.** Were you ever aware of participating in a trial being  
 19 organised by Dr Aronstam?  
 20 **A.** No, not that I can recall.  
 21 **Q.** And then if we go, please, to TREL0000267\_023, please.  
 22 This is an extract from your Treloar's records.  
 23 We can see that the second entry is headed:  
 24 "Autumn Term Assessment."  
 25 If we go over the page, top of the next page, we

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1 together in the same -- well, usually joint. So if  
 2 I'd had, you know, say, three bleeds in two weeks  
 3 into, say, a left ankle, then to break the cycle of  
 4 keep repeating the bleeds, they would give you regular  
 5 treatment on alternate days for a number of weeks to  
 6 try and settle it down so that they broke the cycle of  
 7 keep repeating bleeding over and over again.  
 8 **Q.** Was anything ever said to you about what that might  
 9 mean in terms of possible risks of viral transmission  
 10 because you might be receiving more by way of  
 11 concentrate than would otherwise be the case?  
 12 **A.** No, no.  
 13 **Q.** Can we then go, please, to TREL0000267\_028, please,  
 14 Soumik.  
 15 If we start off by going to the third page. If  
 16 we look at the bottom half of the page we've got an  
 17 example of something here called a "Medical Report".  
 18 This is for 19 June '83. It refers to:  
 19 "Above average number of bleeds.  
 20 "Bleeds mainly into his Right elbow ..."  
 21 There's a reference to three courses of  
 22 prophylaxis, attending physiotherapy, doing some  
 23 remedial gym sessions, and having had a good term.  
 24 Do you know what this document was?  
 25 **A.** I believe it was part of an -- well, this one, an end

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1 see reference to a "Spring Term Assessment", and  
 2 that's a pattern we see repeated.  
 3 Can you recall anything about what appear to be  
 4 these termly assessments?  
 5 **A.** Yeah, I mean, they often did a full range -- they used  
 6 to do a full range of blood tests and then they also  
 7 used to do a full orthopaedic assessment so they would  
 8 measure, you know, joints, how much movement you've  
 9 got in your joints and it's just a full body analysis  
 10 of where, you know, where your joints and muscles are  
 11 having problems. But yeah, it was that blood test,  
 12 but they were pretty much done pretty much at the  
 13 beginning of every term, I would say.  
 14 **Q.** And if we go to the third page, please. We can see  
 15 the second entry down, refers to:  
 16 "Prophylaxis - 20% alternate days ..."  
 17 And that appears to be in relation to your right  
 18 elbow, identified there as a "target joint":  
 19 "... till end of 1/2 term."  
 20 Then if we look at the next entry, sorry, go  
 21 to -- sorry, it's the very bottom of the page. Again,  
 22 we can see reference there to prophylaxis. What can  
 23 you recall about getting treatment on a prophylactic  
 24 basis?  
 25 **A.** It was given when I had a number of bleeds very close

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1 of year school report where they would have several  
 2 pages for each subject. So they'd have English,  
 3 maths, science, and so on. And then at the end you  
 4 would have this medical report to -- and sometimes  
 5 there was a separate physiotherapy report as well.  
 6 And they were generally sent home to parents.  
 7 **Q.** Did you physically take them home to your parents, do  
 8 you know, or were they sent by post?  
 9 **A.** I can't recall. I think we took them. But I can't  
 10 recall 100 per cent.  
 11 **Q.** If we look at the top of the page, I think we've got  
 12 an example of a physiotherapy report. Again, so we've  
 13 got "Summer '83":  
 14 "Lee continues to have regular physio treatment  
 15 for his right elbow which remains a few degrees short  
 16 of full extension. He also attends remedial gym  
 17 sessions and works well."  
 18 So is this your understanding: this was the kind  
 19 of medical information sent from time to time,  
 20 possibly on an annual basis, possibly termly, to your  
 21 parents?  
 22 **A.** Yeah, that I believe was all they tended to get, and,  
 23 you know, it's very, you know, a very loose summary of  
 24 what had happened, but nothing in detail.  
 25 **Q.** Then if we go to the next page we'll see what else was

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1 going on in terms of entries in your medical records  
 2 in June of '83. We can see top of the page it says:  
 3 "29/6/83 Summer Term Assessment"  
 4 I think that says. It's the various entries:  
 5 bleeds, haematology, biochemistry and so on, there's  
 6 a reference to prophylaxis. Then we can see circled  
 7 the word "AIDS", "on 6.3.83".

8 Before we look at what's written underneath,  
 9 Lee, I haven't been able to locate, and I think  
 10 neither have your legal representatives, anything in  
 11 your records which shows anything in particular for  
 12 6 March '83.

13 Do you know what that reference to that date  
 14 means?

15 **A.** Um, I've no idea. I don't know why it's -- I don't  
 16 know why it's there, because, you know, it's a June  
 17 entry. Why would they suddenly mention it -- mention  
 18 that date, that earlier date some, what, three and  
 19 a half months earlier, all of a sudden at that point?  
 20 I don't know.

21 **SIR BRIAN LANGSTAFF:** Is it actually the 6th? Might it be  
 22 the 10th?

23 **MS RICHARDS:** It's possibly the 10th.

24 **SIR BRIAN LANGSTAFF:** Have you checked the 10th?

25 **MS RICHARDS:** Well, we have -- it's not easy to read the

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1 in the past.  
 2 No diarrhoea [possibly] for [more than a week]  
 3 in the past.  
 4 "No cough for [more than a week] in the past.  
 5 "No palpable superficial lymph nodes.  
 6 "No weight loss."  
 7 That appears to be some form of investigation of  
 8 your physical health to consider whether you are  
 9 showing any signs of AIDS.

10 **A.** Yes.

11 **Q.** Was anything said to you at the time to inform you  
 12 that that examination was being undertaken?

13 **A.** Well, obviously I would have been asked those  
 14 questions in order for them to get answers. But why  
 15 they were asking those questions, I just assumed it  
 16 was just a normal medical thing. I didn't know they  
 17 were looking for anything in particular and certainly  
 18 not AIDS.

19 **Q.** If we look at TREL0000267\_005, we've got here what  
 20 seems to be, again, a fairly standard form that  
 21 appears from time to time in your records. This has  
 22 got an entry on the left-hand side for what looks like  
 23 9 Feb '83, and there's reference there to lymphocytes  
 24 and then T cells.

25 Were you ever told anything about monitoring of

79

1 handwriting. If we just go back to page 1, just so  
 2 we're looking at the full set of records, we've got an  
 3 entry there for 15th December '82. If we go to the  
 4 next page, there's an entry at the top which looks  
 5 like 15th March, that's the next entry and it follows  
 6 the format of bleeds, haematology, biochemistry,  
 7 appliances I think is the next one.

8 **SIR BRIAN LANGSTAFF:** Yes.

9 **MS RICHARDS:** Prophylaxis and physiotherapy, but there's  
 10 nothing there that seems to match up with the entry in  
 11 June.

12 **SIR BRIAN LANGSTAFF:** Yeah.

13 **MS RICHARDS:** If we go back to page 4 then, please, Soumik  
 14 and follow through the entry in June, so if we could  
 15 just go to that bit below. Thank you.

16 So "AIDS" on whether it's 6 or 10 March '83.

17 Then we can see a reference to your temperature.

18 I think it says:

19 "No rise in [temperature] for [more than a week]  
 20 in the past."

21 "No ..."

22 Then it might be:

23 "... throat pains or difficulty in swallowing

24 for [more than a week] in the past.

25 "No shortness of breath for [more than a week]

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1 T cells or anything of that kind?

2 **A.** No.

3 **Q.** Can we then, please, look at WITN1541005, please,  
 4 Soumik.

5 If we can go to page 3, there's a letter dated  
 6 30 June 1983, so it's the day after the entry in those  
 7 records we looked at.

8 It's addressed to Dr Crawford in the haematology  
 9 department at the Hammersmith, and then it's said to  
 10 enclose copies of bleeding episodes and transfusions,  
 11 orthopaedic charts and laboratory results, and refers  
 12 to a course of prophylaxis. Then under the heading:

13 "AIDS Related Investigations:

14 "Clinically he exhibits none of the stigmata  
 15 of AIDS. Examination of his superficial lymph nodes  
 16 on 10.3.83 [that suggests you're right in reading the  
 17 handwriting, sir] revealed no palpable lymph nodes.

18 "For your information we have undertaken the  
 19 enclosed AIDS related tests. We are repeating these  
 20 tests before the end of term and will let you have  
 21 a copy when they are available."

22 Were you aware or were your parents made aware,  
 23 to your knowledge, that Treloar's was undertaking what  
 24 it described as "AIDS related investigations" and  
 25 tests?

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1 A. No, because obviously I didn't even know what AIDS was  
 2 at that time. So no, of course not.  
 3 Q. And is this right, there's no equivalent of this  
 4 letter addressed to the Hammersmith being sent to your  
 5 parents?  
 6 A. No.  
 7 Q. Your parents just get the end of term medical report  
 8 that we looked at?  
 9 A. Yeah, that's as far as I know.  
 10 Q. Can we then please go to TREL0000267\_089.  
 11 Now this is a letter from 1985, 19 March 1985.  
 12 It's now being addressed not to the Hammersmith but to  
 13 the Isle of Wight County Hospital. And -- because  
 14 that's now your local centre, is that right?  
 15 A. Yeah, it wasn't a haemophilia centre, but I saw  
 16 a doctor there. I believe they got the product from  
 17 Southampton. But, yeah, that was the doctor who  
 18 I generally saw when I was at home.  
 19 Q. And we can see it says:  
 20 "Dear Doctor ..."  
 21 Refers to you. Then it says:  
 22 "For your information, I enclose copies of:  
 23 "1) Bleeding episodes and transfusions ...  
 24 "2) Laboratory results."  
 25 Then this:

81

1 A. Mm-hm.  
 2 Q. -- at that time.  
 3 We might be able to cast some light on it if we  
 4 look at TREL0000267\_090, please.  
 5 This is a letter of the previous year,  
 6 11 July 1984, from Dr Wassef at Treloar's. It's not  
 7 clear which doctor it's being addressed to but it  
 8 says:  
 9 "For your information, I enclose copies of ..."  
 10 And we see the reference to bleeding episodes,  
 11 transfusions, et cetera.  
 12 Then this:  
 13 "He remains HBsAg negative."  
 14 Then there is a reference to:  
 15 "His Anti HBc was ? weakly positive and Anti HBs  
 16 was positive on specimen taken on 12.1.84."  
 17 So that would suggest that a sample of your  
 18 blood was taken on 12 January, although we can't find  
 19 anything particularly in the records that correlates  
 20 with that.  
 21 A. Yeah.  
 22 Q. And was then stored --  
 23 A. Mm-hm.  
 24 Q. -- and tested for HTLV-III at some point later, second  
 25 half of '84 or at any view by March '85?

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1 "He was tested for Anti HTLV 3 for the first  
 2 time on 12.1.84 and was found to be positive."  
 3 Now, we'll come back in a moment to the  
 4 significance or otherwise of the date of  
 5 12 January 1984, but as at this point in time,  
 6 March '85, were you aware that you were being tested  
 7 for HTLV-III, HIV?  
 8 A. No.  
 9 Q. So you were tested without your knowledge and consent?  
 10 A. Yeah.  
 11 Q. Your mum by this time I think had died?  
 12 A. She died in July '85.  
 13 Q. Were either of your parents, as far as you're aware,  
 14 told that you'd been tested for HIV?  
 15 A. No.  
 16 Q. And we'll come on to how you learnt about your test in  
 17 a few moments, but were you told at this time,  
 18 March 1985, that you'd tested positive for HTLV-III?  
 19 A. No.  
 20 Q. Now, you know the significance of the words "for the  
 21 first time on 12.1.84", Lee, because you've been  
 22 following the evidence, I know.  
 23 A. Yeah.  
 24 Q. And you understand I think, as we do, that HTLV-III  
 25 testing was not available --

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1 A. That's what it looks like, yes.  
 2 Q. Were you aware that your samples were being stored for  
 3 testing?  
 4 A. No.  
 5 Q. And was anything ever said to you about hepatitis B at  
 6 this time?  
 7 A. Um, all I knew was that I was kind of fairly unique  
 8 among the haemophiliacs that I'd never come into  
 9 contact with hepatitis B. I know they were talking  
 10 about doing a vaccination against hepatitis B because  
 11 I hadn't come into contact with it before.  
 12 Q. But any hepatitis B testing was not reported to you?  
 13 A. No, I didn't know, obviously, they were testing for  
 14 it.  
 15 SIR BRIAN LANGSTAFF: Are you going to go through some of  
 16 the records with this in mind? What I have in mind,  
 17 I just happened to notice, as you went through -- it's  
 18 267, so many zeros, 23, then \_002 -- 267\_023, 002.  
 19 MS RICHARDS: So page 2, Soumik.  
 20 So I think it will be TREL0000267\_023.  
 21 SIR BRIAN LANGSTAFF: That's it, thanks.  
 22 MS RICHARDS: And then the second page.  
 23 SIR BRIAN LANGSTAFF: If one looks at the "Biochemistry"  
 24 there, "SGOT persistently raised", then if we go to  
 25 page 267\_028 at page 4, ten days later, I think:

84

1 "Biochemistry: Moderate to marked" -- is it? --  
2 "increase in SGOT."  
3 So it looks as though the records there are of  
4 abnormal SGOT readings.

5 Do you have any clue yourself what SGOT stands  
6 for?

7 **A.** I've no idea.

8 **SIR BRIAN LANGSTAFF:** So it follows that no one ever told  
9 you?

10 **A.** No.

11 **MS RICHARDS:** And we'll come back to this issue when I ask  
12 you about how you found out about hepatitis C. But  
13 was -- were raised liver function tests or concerns  
14 about your liver function ever discussed with you  
15 during your time at Treloar's.

16 **A.** No. No, not at all.

17 **Q.** And then if we go to WITN1541005, please. And if we  
18 go to page 12. If we look at the top of this we can  
19 see it's an "AIDS Surveillance and HIV Death Clinical  
20 Report Form".

21 This is something being reported by the  
22 hospital, St Mary's Hospital Portsmouth, in 1994. But  
23 if we go to the very bottom of the page, and we zoom  
24 in on what's said at the bottom, "Date of first  
25 positive test", so it's the bottom right-hand corner.

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1 actually at the school. And so my recollection, it  
2 was in that Easter holiday of 1986, and it was me  
3 and -- it happened to be the previous witness that  
4 gave evidence.

5 We weren't together, I believe that we were seen  
6 separately. I think I went first. And I believe  
7 Dr Aronstam was there, and almost certainly Dr Wassef.  
8 I believe there was a member of the nursing staff as  
9 well, and it was then that I was told that  
10 I was HTLV-III positive.

11 **Q.** And can you recall what, if anything, they told you  
12 about the significance of that diagnosis?

13 **A.** Well, I knew that -- well, they told me that my life  
14 would be limited. They said they didn't know how long  
15 I would have left. It could be anything from a couple  
16 of years -- they said you could even survive up to  
17 ten years, but the outlook was bleak, basically. That  
18 was my understanding of it.

19 **Q.** And were you given any practical advice or assistance  
20 that you can recall?

21 **A.** Not that I can recall, no. I can't remember much  
22 after that. It was a bit of a shock, obviously.

23 **Q.** Then your recollection is that they -- that the other  
24 boy being told on the same occasion was in fact, by  
25 coincidence, the witness who gave evidence before the

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1 There's reference there to:

2 "Date of first positive test: 6.9.83, last  
3 [negative] 7.6.83", which doesn't seem to match up  
4 with what else we have seen in your records.

5 Do you have any understanding of what those are  
6 referring to?

7 **A.** Well, the only thing they do match is the records from  
8 the National Haemophilia Database, but apart from  
9 that, no.

10 **Q.** And they don't match anything in your Treloar's  
11 records?

12 **A.** Well, no, because they're talking about -- well, we  
13 had January '84 mentioned. No, obviously it doesn't  
14 fall within that range.

15 **Q.** Now what's your recollection of how you learnt that  
16 you had been infected with HIV at Treloar's?

17 **A.** Well, contrary to a lot of the haemophiliacs at  
18 Treloar's, I believe I wasn't told until 1986. And  
19 the reason why I say this is that I was told while  
20 I was at sixth form college, because I remember there  
21 was -- with Treloar's, their holidays, their Easter  
22 holidays and Christmas holidays, were three weeks in  
23 duration, whereas the Alton College holidays, where  
24 I was attending at the time, were only two weeks. So  
25 there was one week where it was just a few of us

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1 break.

2 **A.** Yeah.

3 **Q.** And you were the two being informed on that date, is  
4 your recollection?

5 **A.** Yeah.

6 **Q.** Were you aware, at that point in time, that you'd been  
7 tested for HTLV-III?

8 **A.** No.

9 **Q.** So were you aware of why you were being called in to  
10 see Dr Aronstam and the others?

11 **A.** No. It was, you know, it was something out of the  
12 blue. Because, you know, during the holiday time you  
13 don't expect -- there was very little contact because  
14 obviously the rest of the haemophiliacs would have  
15 gone home for the Easter holidays so, you know, there  
16 was very few staff there during that period. So it  
17 was a complete surprise to find, you know, that they  
18 wanted to see us, you know, in that period.

19 **Q.** And your mum had died by then.

20 **A.** Mm-hm.

21 **Q.** The previous year. You can't, I think, recall whether  
22 you told your dad or whether Treloar's told your dad?

23 **A.** No, I think it was me. I don't think Treloar's  
24 communicated it to him.

25 **Q.** And what was your response, your reaction, to this

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- 1 news?
- 2 **A.** Well, after getting over the initial shock, I think,
- 3 you know, I kind of put it -- tried to put it to the
- 4 back of my mind, to be honest. You know, I didn't
- 5 really want to think about it. You know, I thought,
- 6 well, you know, I just need to kind of get on with
- 7 life the best I can with what time I've got. That was
- 8 my philosophy.
- 9 **Q.** Were you given any form of support or access to
- 10 a counsellor at Treloar's?
- 11 **A.** No.
- 12 **Q.** Or anything like that?
- 13 **A.** No.
- 14 **Q.** And can you recall whether there was any different
- 15 arrangements made for your care at Treloar's, or your
- 16 accommodation?
- 17 **A.** Not that I can think of. I mean by this time I was --
- 18 it was a separate house just for sixth formers. I had
- 19 my own room anyway. I'm not aware of anything
- 20 particular in terms of things like the sharing of
- 21 cutlery or things like that. I don't remember
- 22 anything like that being prevalent.
- 23 **Q.** Now it was a number of years later that you found out
- 24 that you had also been infected with hepatitis C, is
- 25 that right?

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- 1 **Q.** As far as you're aware, is this the first time you
- 2 were tested for hepatitis C?
- 3 **A.** As far as I know, yeah. And I mean on this particular
- 4 occasion, I think I was told that they were going to
- 5 test me for hepatitis C. But that was the first time
- 6 I knew they were going to do that. Whether, you know,
- 7 I'd been tested in the past, I've no idea.
- 8 **Q.** And you've described in your statement someone making
- 9 a cursory comment, "You know you have hepatitis C", or
- 10 something along those lines. Was that on this
- 11 occasion?
- 12 **A.** It would have been the view presumably following
- 13 this -- following, you know, the actual test. So
- 14 yeah, I believe it was probably on that next visit to
- 15 the hospital by, I think it was, Dr Green, the
- 16 consultant at the time.
- 17 **Q.** And that's in Portsmouth?
- 18 **A.** Yes.
- 19 **Q.** And were you ever given -- sorry, not "ever". Were
- 20 you at that point in time, whatever the precise date,
- 21 when you were told you had hepatitis C and what you've
- 22 described in your statement as being by way of
- 23 a "cursory comment" --
- 24 **A.** Mm-hm.
- 25 **Q.** -- were you given at that time any advice or

91

- 1 **A.** Yeah.
- 2 **Q.** If we go to WITN1541006, if we go to the second page
- 3 to start with.
- 4 This is a form, we can see it's relating to your
- 5 time at Treloar's. It's Basingstoke & North Hampshire
- 6 Haematology Service. Dr Aronstam was identified as
- 7 the consultant, the ward is LMTC, Lord Mayor Treloar
- 8 College, and we can see that the test is being
- 9 requested by Dr Wassef, and it's 9 March 1982.
- 10 And what there is there, is a big stamp saying,
- 11 "Hepatitis Risk". Were you ever told that you were
- 12 regarded or -- you were regarded in any sense at all
- 13 as a hepatitis risk?
- 14 **A.** No.
- 15 **Q.** And was the phrase -- I've asked you about
- 16 hepatitis B. Was non-A, non-B hepatitis something
- 17 that was ever discussed with you at Treloar's?
- 18 **A.** I'd heard of it, but, you know, I wasn't aware of
- 19 really what it was or what its effects were or how it
- 20 could affect you. I'd just heard the term.
- 21 **Q.** Then if we go to the next page, this brings us forward
- 22 now to 1997, and we can see here a test for
- 23 hepatitis C and it's a positive test for hepatitis C,
- 24 January 1997.
- 25 **A.** Mm-hm.

90

- 1 information about hepatitis C?
- 2 **A.** No.
- 3 **Q.** And was there any referral of you at that stage to
- 4 a liver specialist or anything along those lines?
- 5 **A.** No.
- 6 **Q.** Now you've told us in your statement -- we can take
- 7 that down, thank you.
- 8 You've told us in your statement that you were
- 9 then tested again in 2002.
- 10 **A.** Yeah.
- 11 **Q.** At a GUM department or GM clinic in Portsmouth, and
- 12 that's the time at which you were first referred to
- 13 a liver unit; is that right?
- 14 **A.** That's right, yeah.
- 15 **Q.** And you were referred to the Royal South Hampshire
- 16 Hospital in Southampton.
- 17 **A.** Mm-hm.
- 18 **Q.** You were seen by Dr Rosenberg for investigation of
- 19 your liver. And what were you told at that point?
- 20 **A.** I was told that the liver was very badly damaged and
- 21 they felt that it was so badly damaged that they
- 22 wouldn't be able to offer me any treatment to, you
- 23 know, eradicate it.
- 24 **Q.** We'll come on to subsequent issues in relation to your
- 25 liver in a moment but if we just go back then to the

92

1 second half of the eighties and early nineties. In  
 2 the years following you being told that you were  
 3 HIV positive, how was your physical health?  
 4 **A.** After when, sorry?  
 5 **Q.** In the second half of the eighties and the very early  
 6 nineties?  
 7 **A.** Yeah, it was okay. I mean, obviously I had the  
 8 problems with my joints, both ankles and my elbow, but  
 9 other than those target joints, I was pretty healthy,  
 10 as far as I knew. I didn't notice any issues that you  
 11 would associate with HIV or hepatitis C at that stage.  
 12 **Q.** You began to receive AZT in 1993.  
 13 **A.** Yeah.  
 14 **Q.** What was the effect of that?  
 15 **A.** I'm just trying to think. I don't think it affected  
 16 me that much because I think I was on the very low  
 17 dose. You know, I don't recall. I mean I think there  
 18 was possibly bouts of diarrhoea and things like that  
 19 but, because the dosage was quite low, I don't think  
 20 it was affecting me that much.  
 21 **Q.** I think it's right that your health then began to  
 22 deteriorate quite markedly --  
 23 **A.** Yeah.  
 24 **Q.** -- in the course of the 1990s.  
 25 **A.** Yeah.

93

1 yeah.  
 2 **Q.** And if we just look at one further document,  
 3 WITN1541010, please, and we go to the second page.  
 4 This is a report being made in October 1994 to  
 5 UKHCDO. It's headed:  
 6 "UK Haemophilia Centre Directors' Survey of  
 7 Patients' HIV infection."  
 8 And we can see that your condition is classified  
 9 as AIDS. There's then details of what you've been  
 10 prescribed if we go further down the page. There's --  
 11 both by way of anti-virals and prophylactic treatment.  
 12 There's then details given of your CD4 count.  
 13 Were you aware that that information or indeed  
 14 any such information about you was being provided to  
 15 UKHCDO?  
 16 **A.** No.  
 17 **Q.** Your consent was not sought for the provision of it?  
 18 **A.** No.  
 19 **Q.** Then you'd been working for P&O and you moved to Dover  
 20 in 2003?  
 21 **A.** Yeah.  
 22 **Q.** And you came under the care of Dr Winter --  
 23 **A.** That's right.  
 24 **Q.** -- at the Canterbury Haemophilia Centre. And he  
 25 became concerned about your liver?

95

1 **Q.** So you were diagnosed with PCP, pneumonia, in the  
 2 autumn of 1994?  
 3 **A.** Yeah, that's right.  
 4 **Q.** And you were 25 at the time and you started to have to  
 5 have lots of treatment in hospital?  
 6 **A.** Yeah, I mean, I was -- I mean, when I had the PCP  
 7 I was in for several weeks. It was kind of very  
 8 isolated, because it was on the east wing at St Mary's  
 9 Hospital in Portsmouth and it was just like a -- it  
 10 seemed like just a big hut, for want of a better term.  
 11 And, you know, I might have been the only person  
 12 there. And, you know, I was kind of out of it quite  
 13 a bit at the time, but yeah, it was a nasty, nasty  
 14 period and, you know, I wasn't sure if I was going to  
 15 survive it or not.  
 16 **Q.** And although you were able to return -- you recovered  
 17 from the pneumonia, you were able to return to work  
 18 for a period of time --  
 19 **A.** Mm-hm.  
 20 **Q.** -- you said in your statement that it took a long time  
 21 to recover your lung capacity and you've had some  
 22 difficulty breathing ever since.  
 23 **A.** Yeah. I mean, I had to be on a nebuliser for some  
 24 time, you know, after being discharged from hospital.  
 25 And, yeah, I was short of breath for quite some time,

94

1 **A.** Yeah.  
 2 **Q.** What steps did he take?  
 3 **A.** He did a referral to Kings College Hospital in London,  
 4 and I was duly sent to have blood tests done there.  
 5 **Q.** And you were called back pretty quickly after the  
 6 blood test results came in?  
 7 **A.** Yeah, I hadn't even got home and I had a call from  
 8 I think it was a Dr Rizzi or something along those  
 9 lines. And he said, you know, "We've got  
 10 abnormalities in your blood test results and we need  
 11 you to come back as soon as possible for more tests."  
 12 **Q.** And you were ultimately told that you were going to  
 13 need a liver transplant?  
 14 **A.** Yeah.  
 15 **Q.** You went on the liver transplant waiting list?  
 16 **A.** Mm-hm.  
 17 **Q.** And you got the call then in 2007, July 2007?  
 18 **A.** Yeah, that's right.  
 19 **Q.** You had the liver transplant?  
 20 **A.** Mm-hm.  
 21 **Q.** How long did you have to be in hospital for? Can you  
 22 recall?  
 23 **A.** I was in hospital three to four weeks, I think. I had  
 24 trouble trying to stabilise the anti-rejection levels  
 25 because once you've had a liver transplant, you have

96



1 to have an anti-rejection drug. In my case it's  
2 called Prograf. And the dosaging on most people is  
3 generally, you know, one tablet twice a day. But  
4 because I was taking HIV medications as well, they  
5 interacted with it, so they had to try and work --  
6 they couldn't work out why the Prograf level was going  
7 through the roof.

8 You know, as I say, when they discovered these  
9 interactions, they had to try and stabilise that, so  
10 it turns out that instead of having it once or twice  
11 a day, I had to finish up having it, at that stage,  
12 once every seven days, because the HIV was kind of --  
13 the HIV meds was elevating the Prograf level so much.  
14 So it took them a while to get that right.

15 **Q.** You talked about what you -- your words in your  
16 statement, Lee, was a bonus of the liver transplant.  
17 What was that?

18 **A.** Well, yeah, I suppose the only positive thing I think  
19 that has come out of it is it actually cured the  
20 haemophilia, because the liver produces the missing  
21 Factor VIII that is missing from most haemophiliacs,  
22 or Factor IX. So, yeah, it was just -- you know,  
23 suddenly I had 60% factor levels all the time and --  
24 so it was quite a shock to suddenly realise that you  
25 don't need to take these Factor VIII injections

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1 **Q.** And you've had to have significant treatment?

2 **A.** Yeah, I had to have, you know, a very aggressive  
3 chemotherapy regime. It goes over number of cycles.  
4 But -- and you have to stay in hospital throughout the  
5 duration of this chemotherapy because it is daily.  
6 Literally, they're giving you all sorts of different  
7 fairly toxic drugs, and it knocks you for six. I mean  
8 it's -- I can't describe how it makes you feel but,  
9 you know, you basically lose -- for example, I had  
10 really bad mouth ulcers. Some of the drugs gave me  
11 hallucinations. I even had a fit while I was actually  
12 in hospital during that period. It was really a  
13 horrible time, and your immune levels basically go to  
14 zero, you know, you just don't have any resistance to  
15 infection at all. So I had to be isolated for, well,  
16 it was up to three months before I was even allowed to  
17 go out for a couple of days just because of the, you  
18 know, because of how low my immune system had  
19 obviously got as a result of all these cancer drugs  
20 that I needed to beat the cancer.

21 **Q.** And you described in your statement being hospitalised  
22 for a number of months.

23 **A.** Yeah.

24 **Q.** And you had to have regular platelet and blood  
25 transfusions?

99

1 anymore that you've been taking all your life.

2 **Q.** You've then had, since then, a number of different  
3 health problems?

4 **A.** Yeah.

5 **Q.** You'd suffered from a form of cancer in October 1998?

6 **A.** Yeah.

7 **Q.** Do you know whether that was associated at all with  
8 the HIV or hepatitis C?

9 **A.** I'm not sure, but it's possible that the speed that it  
10 developed may have been associated with it, from what  
11 I found out since.

12 **Q.** And then in 2013 you were admitted to hospital in  
13 Kent, and you were diagnosed with a very aggressive  
14 form of non-Hodgkin lymphoma, Burkitt lymphoma.

15 **A.** That's right, yeah.

16 **Q.** And you, I think, have researched that and you've  
17 discovered that those that have either had an organ  
18 transplant --

19 **A.** Mm-hm.

20 **Q.** -- which you needed because of your hepatitis C  
21 infection --

22 **A.** Yeah.

23 **Q.** -- or those with HIV have a much higher risk of  
24 developing Burkitt lymphoma; is that right?

25 **A.** Yeah.

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1 **A.** Yeah, I mean that went on even after I was discharged  
2 from hospital, up to, you know, a year, year and  
3 a half later, because, you know, the various drugs  
4 they'd given me had basically knocked everything for  
5 six. My platelet levels were extremely low. I think  
6 they were around about 15 or something like that, and  
7 my HB levels was regularly below 80. So it's -- so,  
8 yeah, it was a regular thing. I had to go to hospital  
9 two or three times a week to be tested, and then as a  
10 result of -- I had to wait for the results of that  
11 test and then that would determine whether I had to  
12 have either platelet transfusion or a blood  
13 transfusion.

14 **Q.** And what was the impact of all the treatment that you  
15 had to have on you, physically and mentally?

16 **A.** Um, it was very draining. As I say, when I was -- you  
17 know, when I was in hospital I couldn't even remember  
18 things like my date of birth or, you know, what day it  
19 was and things like that. But, you know, it very  
20 slowly came back after I came home, but it took a long  
21 time to kind of become, you know, a bit more normal  
22 for want of a better term.

23 **Q.** Now you still had, at this point in time, hepatitis C?

24 **A.** Yeah.

25 **Q.** But you, I think, were treated with harvoni and

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1 ribavirin in 2015?  
 2 **A.** Yeah, what happened was that they were picking up some  
 3 more anomalies on my liver tests. They believe it was  
 4 as a result of having, you know, the various cancer  
 5 drugs that was causing it. So what they wanted to do  
 6 was they wanted me to have this newer treatment as  
 7 soon as possible. They didn't want me to -- they  
 8 certainly didn't want me to -- they knew the liver  
 9 would be reinfected after I'd had the transplant but  
 10 they wanted to hold off as long as possible for, you  
 11 know, for newer drugs to come along that were far less  
 12 aggressive and wouldn't affect in the same way.

13 And at that particular point in time, you know,  
 14 the beginning of 2015, of course, that's when the  
 15 new -- the newer drugs came out and they felt that was  
 16 the right time to then try and, you know, knock the  
 17 hepatitis C out so that I, you know, I wouldn't have  
 18 that to contend with on top of everything else that  
 19 was going on at the time.

20 **Q.** And the virus cleared, the hepatitis C virus cleared  
 21 as a result of that treatment?

22 **A.** Yeah, it did yeah.

23 **Q.** But because of the long-term consequences for your  
 24 liver, the transplanted liver, you still have to  
 25 undergo regular monitoring?

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1 **Q.** And what, broadly speaking, is your current physical  
 2 state of health, Lee?

3 **A.** Well, the latest problem I get now is that, as a  
 4 result of having the liver transplant, I had an  
 5 incisional hernia, and up to about two or three years  
 6 ago I didn't have any problems with it at all, but  
 7 now, in the last year or so, it's starting to give me  
 8 a lot more problems. So I've had a total of six  
 9 episodes in hospital over the past 15 months, I'd say,  
 10 where I've had to go into hospital because I've got  
 11 severe pains across my stomach and I couldn't eat  
 12 anything and I was throwing up, and -- and what it  
 13 turns out is that the hernia is obstructing the bowel.  
 14 So what occasionally happens is that the bowel gets  
 15 completely obstructed, and then they have to do things  
 16 like put an NG tube through my nose to drain my  
 17 stomach and give me fluids. And up to now, touch  
 18 wood, it's kind of cured it each time. But I'm still  
 19 waiting, at the moment, for actually having the hernia  
 20 repaired. Because of Covid that obviously hasn't gone  
 21 ahead. So I'm hopeful in the next few weeks they'll  
 22 actually be able to do it because I've finally had the  
 23 pre-assessment last week, so I'm hoping that will be  
 24 done fairly soon.

25 **Q.** Can I ask you then about the broader impacts of -- on

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1 **A.** Yeah.

2 **Q.** And then in early 2017 you noticed a lump on your lip?

3 **A.** That's right, yeah.

4 **Q.** What was that?

5 **A.** It turns out it was actually a form of skin cancer,  
 6 and it was just like a pimple to start with, sort of  
 7 like I noticed that sort of like at the beginning of  
 8 January. It started to get bigger, so by the  
 9 beginning of March I went to see my GP, and he thought  
 10 it might be cancerous so they then referred me on to  
 11 the hospital. They had a look at it and said they  
 12 thought it was, but weren't sure, but then they  
 13 decided they were going to cut it out but then they  
 14 said, "Oh, it might be too much of an infection risk",  
 15 so there was a lot of umming and aching about when they  
 16 were actually going to do this procedure to actually  
 17 remove it. So by the time they did remove it, it was  
 18 some six months after I noticed it, and from at least  
 19 three months after I initially went to my GP before  
 20 they actually decided where they were actually going  
 21 to do it.

22 **Q.** And again, your understanding is that that particular  
 23 form of carcinoma is more prevalent in patients who  
 24 have had HIV or organ transplants?

25 **A.** Yeah.

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1 your life of being infected with HIV and hepatitis C,  
 2 and all the health consequences that you've described  
 3 that ensued.

4 First of all, in relation to your education,  
 5 what was the impact of the diagnosis on you in terms  
 6 of your approach to education?

7 **A.** Um, well, you know, my education was fine obviously up  
 8 to the diagnosis of HIV. I think I probably --  
 9 I think the diagnosis of HIV affected my performance  
 10 certainly at -- when it came to my A levels. I didn't  
 11 do very well at all at my A levels. I was fortunate  
 12 that I'd done just enough to do a higher national  
 13 diploma and then after that I was able to complete  
 14 a degree. But that's as far as I went, as far as  
 15 education was concerned.

16 **Q.** And you've said in your statement that when you were  
 17 doing your degree, you tended to keep yourself to  
 18 yourself. You had one or two close friends, but you  
 19 didn't want to have to tell people about your HIV.

20 **A.** That's true, yeah. I mean, with regards to -- because  
 21 of the stigma of HIV, I didn't tell anyone, to be  
 22 honest. You know, I didn't want to tell anyone  
 23 because, you know, I was -- you know, for fear of  
 24 rejection. So I, yeah, I just kept myself to myself.

25 I mean, part of it I think, was down to

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1 Treloar's being like an institutional type place, you  
 2 know, where you only sort of, like, had a very small  
 3 circle of friends, to suddenly go to somewhere like  
 4 university where it's far bigger, I struggled to cope  
 5 with that. You know, I had my own room in the halls  
 6 of residence, and, to be honest, I had one or two  
 7 friends, you know, on the course that I was doing, but  
 8 apart from that I kept myself to myself. I stayed in  
 9 my room most of the time. I very occasionally went  
 10 out on student nights out but it wasn't very often.

11 **Q.** You got your degree and you got a work placement at  
 12 P&O Ferries and you started, I think, full time  
 13 employment there in 1993?

14 **A.** Yeah.

15 **Q.** I get the sense from your statement, Lee, that you  
 16 very much enjoyed working?

17 **A.** Mm.

18 **Q.** And enjoyed working there?

19 **A.** Yeah.

20 **Q.** But the various health difficulties that you've  
 21 described impacted upon your employment, is that  
 22 right?

23 **A.** Yeah. I mean, I was okay initially, until it got to  
 24 sort of like the early 2000s, when I think the --  
 25 obviously, the effects of the hepatitis C was kind of

105

1 **A.** Yeah.

2 **Q.** And you believe that that redundancy, you being the  
 3 person selected for redundancy, was ultimately because  
 4 of the health issues which had resulted in you not  
 5 being able to progress in the way that you would  
 6 otherwise have anticipated?

7 **A.** Yeah. I mean, I came back to work, but I was still  
 8 getting very tired and I was falling asleep at my desk  
 9 a lot. You know, I just wasn't -- my heart really  
 10 wasn't in it anymore, if I was honest. You know,  
 11 I was just too tired and so on. Even after having the  
 12 transplant, you know, it was just very tiring. And  
 13 I just felt that, you know, it was, you know, it was  
 14 a struggle. But then I got of the news that --  
 15 because I'd recently only bought a house, sort of,  
 16 like, a few months before I was told that I was at  
 17 risk of redundancy. And, you know -- and it was to be  
 18 a -- basically they would merge two roles into one and  
 19 it was going to be me and this other person who had  
 20 been covering for my section, you know. It was just  
 21 going to be a straight contest between the two of us.

22 And I think it was inevitable really that, you  
 23 know, I probably wasn't up to it at that time, and as  
 24 a result, that's why I think I was made redundant.

25 **Q.** And in terms of personal relationships, you've

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1 coming up, and I found that I wasn't able to -- really  
 2 was struggling to sleep. My sleep pattern was  
 3 severely disrupted. So I was finding that I was --  
 4 you know, I was -- I was staying awake all night and  
 5 then sleeping during the morning. So at that stage,  
 6 work was quite accommodating, that they would change  
 7 my hours so that I kind of would start at midday and  
 8 then finish about 8 or 9 o'clock at night because then  
 9 I was -- I felt I was kind of at my best. And so,  
 10 yeah, they made allowances for that.

11 **Q.** Then there was a point in time with your work where  
 12 you had to effectively, because of the health  
 13 difficulties, make a sideways move rather than get  
 14 promotion?

15 **A.** Yeah, because they knew the liver transplant was  
 16 coming up and I was going to be out of the business  
 17 for, you know, three months at least, they felt that,  
 18 you know, they couldn't afford me -- to have no leader  
 19 of their team for that length of time, so they did  
 20 a sideways move for me to just work on individual  
 21 projects, should I say, and they got another person  
 22 who was head of another section to cover my section as  
 23 well.

24 **Q.** And ultimately, you were made redundant in, I think,  
 25 2008?

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1 described in your statement the difficulties in  
 2 relation to that, because you were determined, if you  
 3 met someone and had a relationship with them, you  
 4 would tell them about your condition.

5 **A.** Yeah.

6 **Q.** But that made you hold back, and when you did tell  
 7 someone, sometimes there was sympathy, sometimes there  
 8 was shock.

9 **A.** Yeah. I mean, you know, at the end of the day, you  
 10 know, I wouldn't go ahead and meet somebody without  
 11 telling them beforehand because obviously, you know,  
 12 the nature of dating, you know, in this day and age is  
 13 more often through, you know, through messaging apps  
 14 and dating sites and things like that. And, yeah,  
 15 I mean -- yeah, I didn't want to put myself in the  
 16 position where -- you know, I had to be sure that the  
 17 relationship was going somewhere. But, on the other  
 18 hand, I didn't want to tell them in case I got an  
 19 immediate rejection after it.

20 So, you know, it's do you tell them early --  
 21 it's like what was said earlier: do you tell them  
 22 early on or do you wait and then -- then they say,  
 23 "Well, why didn't you tell me before?" You know, it's  
 24 that dilemma.

25 **Q.** And you did meet someone?

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- 1 A. Mm-hm.  
 2 Q. Tracey.  
 3 A. Yeah.  
 4 Q. And you got married in 2008.  
 5 A. Mm-hm.  
 6 Q. But then that's when everything went wrong in terms of  
 7 your employment?  
 8 A. Yeah.  
 9 Q. You lost the house?  
 10 A. Yeah, because, you know, once I'd lost my job  
 11 I couldn't afford to pay the mortgage, and -- yeah,  
 12 I mean, debts built up. And yeah, eventually the  
 13 house got repossessed because I couldn't find any  
 14 other work obviously because of my illnesses.  
 15 Q. And eventually the marriage broke down?  
 16 A. It did, yeah.  
 17 Q. Although you're still, I think, on good terms?  
 18 A. Oh, yeah, we're still really good friends but, you  
 19 know ...  
 20 Q. And you would attribute that in large measure to  
 21 everything else that was happening because of your  
 22 health, the financial difficulties --  
 23 A. Yeah. I mean, there was a lot going on anyway, but  
 24 the health issues on top were, I think, just, you  
 25 know, the tip over the edge, if you like.

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- 1 a part payment towards a Motability car, the advance  
 2 payment on my car. I think that was the only thing  
 3 I got out of them.  
 4 But other than that, it was just going through  
 5 the process of having to divulge all the -- you know,  
 6 all your income and expenditure. And the fact that  
 7 you had to divulge the income of other people as well,  
 8 that was in your household, you know, I was very  
 9 unwilling to do that, and I felt it was wrong they  
 10 were going to take into account the expenditure --  
 11 I had a -- I had a lodger living with me at the time  
 12 and, you know -- and she wasn't prepared to obviously  
 13 give out her financial information, and, you know,  
 14 I felt it was wrong that they should insist that,  
 15 because somebody was living under the same roof as  
 16 you, their income should be taken into account as well  
 17 as yours.  
 18 Q. And in terms of the Skipton Fund payments, although  
 19 you received the lump sum payments, the timing of the  
 20 stage 2 payment came too late to save your house from  
 21 being repossessed?  
 22 A. Yeah, it was, literally a month. I literally got the  
 23 payment a month after the house was actually  
 24 repossessed.  
 25 Q. And you'd said this in your statement, I just want to

111

- 1 Q. Can I just ask you, then, your experience of the  
 2 trusts and schemes, the Macfarlane Trust in  
 3 particular.  
 4 You've talked in your statement about when you  
 5 were experiencing particular financial difficulties.  
 6 You tried to ask the Macfarlane Trust for assistance  
 7 with mortgage or with debt repayments. What happened?  
 8 A. Well, they said they couldn't help me, but they  
 9 actually sent I think it was somebody from the  
 10 Terrence Higgins Trust, somebody to talk about debt  
 11 management. But they came to visit me and -- but, to  
 12 be honest, they weren't any help at all. You know, it  
 13 was -- they talked about it, but they couldn't help me  
 14 financially in any way, they could only give me debt  
 15 advice, but -- and I could get that anyway. So  
 16 I didn't feel that was much help.  
 17 Q. And you said in your statement:  
 18 "My experience with the Macfarlane Trust was  
 19 that they would not consider anything until every  
 20 possible avenue was explored with other organisations  
 21 first. The whole process was just so degrading."  
 22 A. Yeah, it was. I mean, they -- you know, they insisted  
 23 on, you know, quotes -- various quotes for any --  
 24 anything that you want. I think the only thing I did  
 25 get out of them, from recollection, is I think I had

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- 1 read a paragraph from your statement, Lee.  
 2 A. Mm-hm.  
 3 Q. "As a result of being infected with contaminated blood  
 4 products I have lost my job, my home, my wife, my  
 5 ability to have children, the possibility of a decent  
 6 pension, life insurance, my future earnings potential,  
 7 had numerous serious health issues and who knows what  
 8 other health condition could be yet to materialise.  
 9 Ironically, the only thing I have gained is the cure  
 10 for Haemophilia, the very condition whose treatment  
 11 caused all the problems in the first place. Having  
 12 said all that, at least I am still here, against all  
 13 the odds, trying to live my life in the best way  
 14 I can."  
 15 A. That's fair.  
 16 **MS RICHARDS:** Those are the questions I have for you, but  
 17 I'm just going to first of all ask Mr Snowden, who  
 18 represents you, if he has got anything further he  
 19 would like me to ask.  
 20 Sir Brian, do you have questions for Lee?  
 21 **Questions from SIR BRIAN LANGSTAFF**  
 22 **SIR BRIAN LANGSTAFF:** Yes, just a couple of questions.  
 23 The first is that when you went to self-treat at  
 24 Treloar's, you described a chart.  
 25 A. Yeah.

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1 **SIR BRIAN LANGSTAFF:** And that told you how many units you  
 2 would get for a certain percentage of Factor VIII in  
 3 your bloodstream.  
 4 **A.** That's right.  
 5 **SIR BRIAN LANGSTAFF:** Was this one chart for whatever  
 6 concentrate you had or were there different charts for  
 7 different brands?  
 8 **A.** No, there was one chart. I remember distinctly, it  
 9 depended on I think it was -- I can't remember if it  
 10 was based on body mass or something like -- or  
 11 something to do with surface area of your body.  
 12 I distinctly remember there was one chart for somebody  
 13 who was, let's say, smaller and then another chart for  
 14 somebody who was larger, shall we say. But that was  
 15 it. There was no differentiation between different  
 16 products or anything. It was all the same chart.  
 17 **SIR BRIAN LANGSTAFF:** So high potency would have exactly  
 18 the same as anything else, would it?  
 19 **A.** Um ... I don't know because I'd never had high  
 20 potency.  
 21 **SIR BRIAN LANGSTAFF:** Very well.  
 22 **A.** But I don't know how that was worked out.  
 23 **SIR BRIAN LANGSTAFF:** The other question is very  
 24 different. It really was, as counsel was summarising  
 25 in your own words everything that had happened to you,

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1 when you came to the Macfarlane Trust, described  
 2 yourself as feeling it demeaning, degrading, that you  
 3 had to divulge all that information --  
 4 **A.** Yeah.  
 5 **SIR BRIAN LANGSTAFF:** -- why are you here sitting in the  
 6 chair there telling us all about what has happened to  
 7 you?  
 8 **A.** I just now feel that, you know, the story has to be  
 9 told, because, you know, we've all, all of us, both  
 10 the haemophiliacs at Treloar's and obviously the wider  
 11 infected blood community, it's, you know, I, you know,  
 12 I just had to -- I felt that I had to put it out there  
 13 along with, you know, along with others because I feel  
 14 it's important that people know how badly that we've  
 15 all been affected by this, you know, this, you know,  
 16 this -- having the infected blood. It's -- I just  
 17 needed to, you know, you need to hear, as you said  
 18 yourself, you know, you want to hear as many different  
 19 stories as possible, and I felt that mine was  
 20 something just a bit different from others.  
 21 **SIR BRIAN LANGSTAFF:** Indeed. Thank you.  
 22 **MS RICHARDS:** Lee, is there anything you would like to  
 23 add?  
 24 **THE WITNESS:** Yeah, I'd just like to read something if  
 25 I may.

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1 I'd been reflecting that you've sat there in your  
 2 matter of fact way, described a whole series of events  
 3 happening to you all because not as you put it the  
 4 health issues on top -- I think they were underneath,  
 5 weren't they, everything that had happened to you?  
 6 **A.** Yeah.  
 7 **SIR BRIAN LANGSTAFF:** How have you managed it?  
 8 **A.** People often ask me that. I don't know. I've tended  
 9 to always have like a -- I try to have a positive  
 10 outlook on life. And, you know, it just, you know,  
 11 it's just another thing to battle with but I try not  
 12 to let it get me down. You know, I try to, you know,  
 13 put the problems at the back of my mind and try and  
 14 see something positive out of it. And that's the way  
 15 I've always lived. And I think maybe that's part of  
 16 the reason why I'm still here, because I haven't  
 17 allowed it to get me down. I haven't, you know,  
 18 tried -- I haven't really suffered from depression or  
 19 anything like that. You know, I just battle on, as it  
 20 were, and say oh it's just another thing. You know,  
 21 next. You know.  
 22 **SIR BRIAN LANGSTAFF:** And for someone who, when they were  
 23 at university, kept themselves to themselves because  
 24 of the fear of disclosing that you were HIV positive,  
 25 had seen relationships founder for that reason, and

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1 Firstly, I'd like to pay tribute to all the  
 2 haemophiliacs of Treloar's. Many would say that we  
 3 put the life into Treloar's. Some would push the  
 4 boundaries while we were there but on the whole  
 5 I think we were a close knit bunch, and many close  
 6 friendships were formed between us. I personally  
 7 enjoyed my time at the school and kept in touch with  
 8 some of the staff after leaving. It was through them  
 9 that I started to learn that, one after another, the  
 10 haemophiliacs were dying of AIDS. I had a close call  
 11 too. But somehow managed to survive.  
 12 Out of the few of us that are left, struggling  
 13 on, some understandably just want to get on with their  
 14 lives. The rest demand the truth for all those that  
 15 they made a promise to get answers for.  
 16 We have heard clinicians from many Haemophilia  
 17 Centres give evidence. Unfortunately, most of the key  
 18 doctors at Treloar's are no longer alive, so  
 19 I appreciate that the job of the Inquiry is made more  
 20 difficult by having to piece together many incomplete  
 21 records and to rely on the reflections of those of us  
 22 who were there at the time.  
 23 As well as the families of those haemophiliacs  
 24 that have sadly passed, such as parents that should  
 25 never have had to bury their sons, I also want to

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1 spare a thought for the students at Treloar's that  
2 were not haemophiliacs who had formed close  
3 friendships and relationships with the haemophiliacs  
4 during this time, and also the care staff and teachers  
5 who had little or no knowledge of what was going on at  
6 the medical centre that were left to pick up the  
7 pieces.

8 With the exception of one or two staff members  
9 I lost touch with most of those I went to school with  
10 after I left in 1987. It was only through reading  
11 a local newspaper article in 2015 featuring the late  
12 Steve Diamond and his wife Sue that I became aware of  
13 tainted blood, and through joining them I was  
14 reacquainted with several former school friends and  
15 have also made lifelong friends with many others in  
16 the group. This meant I no longer felt isolated and  
17 we could talk about our experiences openly with people  
18 who understand. Love you guys. And Steve, you really  
19 were a diamond and are very much missed.

20 I also want to pay tribute to those who have  
21 campaigned tirelessly for many years, including those  
22 who have sadly passed, and those that gave evidence  
23 a few weeks ago. It is in part down to their sheer  
24 doggedness and determination that we now have  
25 this Inquiry. So thank you.

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1 for today. This afternoon I will resume the  
2 examination of the documents about Treloar's that I  
3 began on Monday morning.

4 **SIR BRIAN LANGSTAFF:** Yes, well, we'll start that at 2.30.  
5 So 2.30.

6 **(1.25 pm)**

7 **(The luncheon adjournment)**

8 **(2.30 pm)**

9 **Presentation by MS RICHARDS**

10 **SIR BRIAN LANGSTAFF:** Yes?

11 **MS RICHARDS:** Sir, we've looked on Monday at the annual  
12 returns up to and including 1985. I'm not going to go  
13 to any of the later annual returns but I'm going to  
14 look next at some of the documents on a similar theme  
15 exploring what products were used in what volume, and  
16 if there was any discernible policy in terms of the  
17 use of products.

18 If we start with TREL0000059\_008, please.

19 This in fact is a letter about the use of  
20 cryoprecipitate in May 1973 from a consultant  
21 pathologist in Warwickshire to Dr Aronstam, and about  
22 an individual pupil. But it's interesting to note, if  
23 we pick it up halfway down that paragraph:

24 "One point which interests me is the amount of

25 Cryoprecipitate which I administered is rather less

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1 I hope that the Inquiry can bring a closure to  
2 all those who continue to suffer and, although it  
3 cannot bring loved ones back or repair the damage  
4 done, I hope that at least it may lead to some kind of  
5 compensation to everyone infected or affected,  
6 including bereaved parents and children who currently  
7 get nothing.

8 I thank Sir Brian, the Inquiry team, and my  
9 legal representatives for all the work so far and wish  
10 the Inquiry well.

11 [Applause]

12 **SIR BRIAN LANGSTAFF:** It doesn't surprise me at all that  
13 you've had the prolonged applause that you have,  
14 because it's been obvious from your last remarks, as  
15 it has throughout, that you have really sat there, a  
16 fairly private person in many ways, saying what you  
17 have about yourself as a matter of fact, because you  
18 value other people. You haven't really done it for  
19 yourself, I think you've done it for others. And that  
20 I think is why you've had the recognition from  
21 everyone here. And I just want to add my thanks to  
22 you for, as you say, giving us another, different  
23 story. Thank you.

24 **THE WITNESS:** Thank you.

25 **MS RICHARDS:** Sir, that's the last of the oral evidence

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1 than that given by yourselves. I have found that with  
2 the admittedly relatively minor bleeds which [he] has  
3 had here, a total of eight units given over two days  
4 seems to control the haemorrhage adequately. If you  
5 feel that it would be better to give larger doses  
6 however, I will bring my treatment into line with  
7 yours."

8 Again, that's an early indication of a theme  
9 which emerges from some of the documents about the  
10 volume of product used in reading pupils at the  
11 school.

12 In terms of when concentrates were first  
13 introduced, if we look at DHSC0100025\_098.

14 This is an early reference or relatively early  
15 reference to the use of concentrates. It's a letter  
16 from Dr Rainsford to Dr Maycock, 18 March 1969, and it  
17 refers in the first paragraph:

18 "Many thanks for your letter ... and for the six  
19 bottles of dried concentrate. I certainly feel safer  
20 now that we have something in reserve for emergency  
21 purposes."

22 Then the letter continues with some information  
23 about supplies to Treloar's. Dr Rainsford says in the  
24 second paragraph:

25 "... the needs of the college for AHG now are no

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1 heavier than they would have been before I came here  
2 had the boys been adequately treated. I have no  
3 information concerning any estimates having been made  
4 for AHG before I ever came here. Furthermore, it is  
5 only now that any accurate figures are available upon  
6 which any estimate could be based."

7 It appears to be Dr Rainsford's view that there  
8 had been under-treatment prior to his arrival at the  
9 college, the school.

10 Then he says that he had:

11 "... discussed the supply of both cryoglobulin  
12 and fresh frozen plasma with Zeitlin ..."

13 And that's a reference to the doctor at the  
14 South London Transfusion Service, I think. We'll see  
15 there a reply in a little while.

16 "... and at that time Zeitlin informed me that  
17 his output of cryoglobulin could not exceed more than  
18 100 bags a week. He did, however, agree to supply me  
19 with 15 bottles of fresh frozen plasma and 24 bags of  
20 cryo twice weekly. He has, however, not always been  
21 able to maintain this. I now find that the bottles of  
22 fresh frozen plasma we receive from Zeitlin only  
23 contain approximately 300ml and I had assumed that  
24 they would contain 450ml. Each case needing treatment  
25 requires on an average 900ml of FFP or 9 bags of cryo.

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1 If we can then look, please, at HHFT0000916\_003.

2 This is at the end or towards the end of the  
3 1970s now and it's an exchange of correspondence  
4 between Dr Craske and Dr Aronstam that we've looked at  
5 previously, but not necessarily in the context of  
6 focusing on what it means for Treloar's.

7 So 10 May 1979, Dr Craske wrote to Dr Aronstam  
8 in the terms we see set out here, with, in the  
9 second -- well, I'll pick it up actually in the first  
10 paragraph:

11 "You'll be aware that the study of NHS  
12 Factor VIII has now been going for almost a year; I've  
13 not so far been notified of any cases of hepatitis in  
14 patients treated with the designated batches used in  
15 this study. Perhaps you could unless let me know  
16 whether in actual fact you have had any cases after  
17 these batches.

18 "I would suggest that for the second year of the  
19 study some of this material should be used to treat  
20 mild haemophiliacs coming up for non-urgent operations  
21 such as tooth extraction. We found out from  
22 observations at Oxford this is the best way of finding  
23 out whether the material is associated with cases of  
24 hepatitis, as most patients treated under these  
25 circumstances will be susceptible to non-A, non-B

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1 Our records over a period of six months show that we  
2 have on an average three cases to treat a day. You  
3 will realise, therefore, how very short we are of  
4 these materials and we often have nothing in reserve  
5 should an emergency arise, except what you supply in  
6 the way of dried concentrate.

7 "Personally I feel 100 bags of cryo a week is  
8 a ridiculously small output for a whole Region,  
9 especially so when it is remembered that one case  
10 requiring open surgery could mop up the whole of it."

11 That gives some insight into Dr Rainsford's  
12 approach as at 1969.

13 In terms, then, of evidence from individual  
14 witnesses who attended the school, there are witnesses  
15 who recall receiving fresh frozen plasma in the late  
16 sixties at Treloar's, and then starting to receive  
17 cryoprecipitate, '69, '70, '71. Then there is  
18 evidence of pupils receiving concentrates as treatment  
19 from about 1972 predominantly.

20 We'll look at some of the studies when we come  
21 on to research later in the week. But there are  
22 references to pupils receiving prophylactic trials of  
23 Factor VIII in around 1973. Then, as we saw from the  
24 annual returns as we go through the 1970s, the use of  
25 factor concentrates increases substantially.

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1 viruses in the transfused material.

2 "I am aware that you may prefer to use  
3 commercial concentrate for some patients in this  
4 class, but it would provide valuable information if  
5 you could use some of the material issued in the way  
6 I have suggested."

7 Then we have a handwritten entry at the bottom:

8 "I realise that the above suggestion does not  
9 apply to the LMT boys."

10 Then we've looked again previously at  
11 Dr Aronstam's response but if we can look at it again,  
12 HHFT0000916\_002. This is Dr Aronstam's letter to  
13 Dr Craske of 14 May 1979:

14 "We have not had any cases of hepatitis  
15 following NHS Factor VIII. As far as your suggestion  
16 about transfusing mild haemophiliacs with this  
17 material is concerned, I totally disagree with this  
18 concept. I do not wish any of my mild haemophiliacs  
19 to develop hepatitis in any form and therefore adopt  
20 the policy of either using DDAVP or Cryoprecipitate."

21 Pausing there, it needs to be borne in mind of  
22 course that Dr Aronstam was responsible not just for  
23 the treatment of the pupils at Treloar's but for the  
24 treatment of the population more generally in the  
25 local area. And the Centre, whilst located at the

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1 school, was a Haemophilia Centre which treated people  
2 who were not pupils at the school.

3 We're not aware of there being, in any  
4 significant number, if in any number at all, pupils  
5 who were mild haemophiliacs.

6 **SIR BRIAN LANGSTAFF:** It will be counterintuitive to think  
7 they would be there.

8 **MS RICHARDS:** It would.

9 **SIR BRIAN LANGSTAFF:** Because there would be no reason for  
10 them not to be in mainstream education.

11 **MS RICHARDS:** Precisely. And perhaps implausible to think  
12 there would be many local education authorities  
13 willing to fund a placement at a boarding school for  
14 someone with mild haemophilia. And certainly, not  
15 just from the oral evidence we've heard, but in terms  
16 of the records that the Inquiry has examined, they  
17 have related invariably to patients with severe  
18 haemophilia.

19 **SIR BRIAN LANGSTAFF:** So this response is not Dr Aronstam  
20 taking a stand on behalf of his boys, but on behalf of  
21 his adult mild haemophiliac patients?

22 **MS RICHARDS:** That would certainly seem to be the logical  
23 deduction, sir, yes.

24 **SIR BRIAN LANGSTAFF:** Yes.

25 **MS RICHARDS:** With regard, then, to the students at the

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1 returned from a spell in New York last summer, as  
2 Director in charge of the whole unit and also the  
3 Haematology/Pathology facility at Basingstoke.  
4 "All orders for the Wessex area are processed  
5 through the buying office in Winchester, but Aronstam  
6 makes the decisions, as he is by far the biggest user.  
7 His first requirement is convenience of  
8 administration, since they can often have 15 infusions  
9 to give at a time. The six months study of all  
10 commercial concentrates last year showed Hemofil and  
11 Factorate to be better than Koate in this respect. In  
12 his opinion, solubility is slower with our product.  
13 It is worth going back, if we can provide evidence to  
14 the contrary."

15 Then in the next paragraph there is a discussion  
16 about Dr Aronstam's methods of treatment of patients  
17 with inhibitors and a reference to including Hyate in  
18 their considerations, a reference in the next  
19 paragraph to Dr Aronstam being interested in the PE  
20 material. I think that's the polyelectrolyte  
21 material, and:

22 "He believes animal [presumably a reference to  
23 the porcine product] has a place in treatment, but has  
24 never used it."

25 Then perhaps we don't need to go back to this

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1 school with severe haemophilia, there does not appear  
2 to have been any specific policy in place in terms of  
3 how to treat them. We've seen from the annual returns  
4 very significant volumes of factor concentrate used  
5 and a range of different commercial concentrates as  
6 well as NHS concentrate as well.

7 And there doesn't appear to be anything,  
8 certainly not in any of the documentation we've seen,  
9 which suggests any particular type of policy of  
10 reserving one particular type of concentrate for one  
11 particular type of pupil or limiting pupils' exposure  
12 to concentrates, or limiting pupils' exposure to  
13 multiple batches. On the contrary, the evidence  
14 appears to suggest very much the opposite in relation  
15 to that.

16 If we look at that again, again in terms of just  
17 trying to get an understanding to Dr Aronstam's  
18 approach to treatment, IPSN0000331\_008.

19 This is a file note of a meeting dated  
20 31 August 1978. The meeting is said to have taken  
21 place on 25 August 1978. It's a meeting between,  
22 I think, the director of Speywood or a representative  
23 of Speywood and Dr Aronstam.

24 It says in the first paragraph:

25 "Tony Aronstam, one time Haematologist at LMT,

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1 document, we can just pick up a couple of other  
2 themes, it says:

3 "He mentioned Rizza's theory for the treatment  
4 of inhibitors, by giving frequent low doses of human  
5 Factor VIII. This is said to reduce the inhibitor  
6 level.

7 "I referred to the hepatitis problem with Armour  
8 material, but this was discounted. Aronstam believes  
9 hepatitis is strictly a function of the number of  
10 doses given and said that 48 of his present patients  
11 at LMT have had it and it frequently recurs."

12 Again, obviously, I'll come back to issues about  
13 hepatitis at a later stage.

14 So that is a report, and obviously it's  
15 secondhand, but a report saying that Dr Aronstam's  
16 first requirement was convenience of administration,  
17 and then express preference for Hemofil and Factorate.

18 Then if we go to the witness statement of  
19 Dr Painter, which is WITN5277001.

20 And Dr Painter, you will recall, was a clinical  
21 officer within the Hampshire Health Authority and  
22 working at Treloar's for a period between 1977 and  
23 1978. If we go to paragraph 17, I think it is -- it  
24 is the top of page 9, please, Soumik.

25 So he was asked about how decisions were taken

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1 about what products to use for individual patients and  
2 he said this:

3 "Apart from pupils who had been enrolled in the  
4 'hepatitis study' (started before I took up post)  
5 I don't know how decisions were made as to which  
6 product someone should receive. I imagine it was  
7 dictated to a certain extent by what material was  
8 available at Treloar's at any given time.

9 "When it came to the concentrates, Hemofil was  
10 the preferred option because it went into solution  
11 more quickly than the others especially the 'Lister'  
12 product which could take up to 20 minutes or more to  
13 dissolve if I recall correctly."

14 Sir, that's consistent with what we saw in the  
15 Speywood note of a recollection that convenience of  
16 administration was a factor at least.

17 The evidence that we've heard this week, the  
18 evidence we've heard previously from Treloar's pupils,  
19 and the annual returns, all indicate that individual  
20 pupils were given a variety of products, and we can  
21 just look at a handful of further documents by way of  
22 example.

23 If we start with TREL0000328\_077, please. We  
24 see here April 1979, a letter from Dr Swinburne to a  
25 doctor in Scarborough. It refers to the patient

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1 limit exposure to multiple batches, multiple donors,  
2 different types of concentrate.

3 **SIR BRIAN LANGSTAFF:** Well, quite the reverse.

4 **MS RICHARDS:** Yes.

5 **SIR BRIAN LANGSTAFF:** And it may fit with one of the  
6 reasons I asked the question I did of Lee Stay, was  
7 that it appears that all commercial concentrate, all  
8 concentrates were treated in exactly the same way when  
9 it came to how much you needed, so you could pick and  
10 mix.

11 **MS RICHARDS:** Yes.

12 If we could go to WITN1592011.

13 This, I think, is a document that we looked at  
14 when Richard Warwick gave his evidence in 2019 but we  
15 can see it's a letter from Dr Aronstam to Dr Swinburne  
16 dated 23 April 1979, and we can see in the first  
17 paragraph it says:

18 "Thank you for sending me a copy of the letter  
19 you wrote to Dr Whitehead in which you state that you  
20 think it would be wise for us to stick to one product  
21 and suggesting Hemofil.

22 "Since Richard has been with us, he has received  
23 a total of 208 transfusions. The material he has  
24 received is broken down as follows ..."

25 Then we can see:

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1 having come to see Dr Swinburne. She'd studied his  
2 treatment records from Lord Mayor Treloar, and then we  
3 can see the reference in the second paragraph:

4 "I note that he received a variety of products  
5 at school, sometimes three different products within  
6 2 or 3 days."

7 If we go to TREL0000056\_014, this is -- again,  
8 this is a different pupil. This is in relation to the  
9 mid-1970s and we can see there Kryobulin, Kryobulin,  
10 different batch of Kryobulin, and then Lister, two  
11 different batches, and then a further two different  
12 batches of Kryobulin, and so on.

13 And then if we look a little further down the  
14 page, yes, sir, we can see, over a period of number of  
15 weeks, a range of --

16 **SIR BRIAN LANGSTAFF:** Yet if we look at the bottom of the  
17 page, where we skipped -- can we just go up? Keep it  
18 there, please, Soumik.

19 At 27.5.75, part of the Kryobulin is the  
20 batch 09N6974, and then that appears to be still  
21 available on 1 July when it's given then.

22 **MS RICHARDS:** Absolutely.

23 **SIR BRIAN LANGSTAFF:** So it's part used, part reused.

24 **MS RICHARDS:** Yes. Yes. And there's appears to be no  
25 obvious design in terms of trying to adhere to or

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1 "Kryobulin 80

2 "Lister 73

3 "Factorate 24

4 "Hemofil 16

5 "Koate 15"

6 Then the view that is expressed in the final  
7 paragraph says:

8 "However, his ability to take over 200  
9 transfusions of concentrate without any reaction  
10 suggests that there is not really a problem here and  
11 in view of the difficulties we experience in supplying  
12 replacement material for 55 severe haemophiliacs,  
13 I would prefer not to confine Richard to a single  
14 Concentrate."

15 So again, there an express rejection of  
16 a proposal being made to confine exposure to a single  
17 concentrate and saying don't want to do that, and  
18 referring again to questions of what might be regarded  
19 as convenience in terms of having 55 patients to  
20 treat.

21 **SIR BRIAN LANGSTAFF:** Yes.

22 **MS RICHARDS:** Again, I won't put every document on screen  
23 but we've got multiple witness statements from either  
24 those who were at Treloar's or those who are the  
25 relatives of individuals who attended Treloar's, which

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1 tell the same story.  
2 Sir, we have, for example, a statement -- well,  
3 actually I will put it up.

4 WITN1353001. We can go to page 2.

5 This is a statement from a widow talking about  
6 her late husband Charlie, and in paragraph 8 she says:

7 "From September 1979 to July 1988, Charlie  
8 attended the Lord Mayor Treloar College ... where he  
9 was treated with Hemofil, Factorate, Koate and Lister  
10 and Kryob", so Kryobulin.

11 So there within a single school year we see  
12 reference to five different types of concentrate being  
13 used.

14 Then if we go to WITN1202001. If you haven't  
15 got it, don't worry.

16 If you go to the third page, we can just see, if  
17 we look at paragraph 14, it refers again to attendance  
18 at Treloar's.

19 "This shows that I was receiving various brands  
20 of [Factor] VIII products from as early as May 1974,  
21 when I received Hemofil. Whilst at Treloar [this was  
22 someone who left in 1978] I was also treated with  
23 Lister Concentrate, Kryobulin, Koate and Factorate."

24 So the recollection of individual witnesses is  
25 entirely consistent with the inferences that you might

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1 whether the -- this was effectively chosen at one  
2 inference being for convenience, or whether it was  
3 forced upon the centre, because they couldn't get  
4 enough products, and so had to pick and mix  
5 themselves. But given the way in which the products  
6 were used interchangeably almost for individuals,  
7 despite obviously having the product in stock, it's  
8 difficult to draw that conclusion, I think.

9 **MS RICHARDS:** Yes. We'll look in a few minutes at some  
10 documents which show Dr Aronstam raising concerns  
11 about insufficient supplies of NHS concentrate.  
12 Whether he was unable to obtain a sufficient supply of  
13 a single concentrate, there's no particular evidence  
14 to show that he was, but the documentation doesn't  
15 address that one way or another.

16 But if one assumes, as it were, that perhaps  
17 that was the situation, and he had to buy a range of  
18 different commercial concentrates or the centre had to  
19 purchase a range of different commercial concentrates,  
20 what one then doesn't see is any attempt to say,  
21 "Well, I've got enough Kryobulin to treat 12 patients  
22 of my 55, those 12 will only get Kryobulin. The next  
23 12 will only get Hemofil. The next 12 ..." other than  
24 when it comes to certain pieces of research and study,  
25 and we'll look at that later in the week, then it does

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1 wish to consider drawing from the annual return data  
2 that we looked at.

3 We saw yesterday during --

4 **SIR BRIAN LANGSTAFF:** The total number being treated for  
5 severe haemophilia was very little different from the  
6 total number in quite a number of other centres we've  
7 looked at, is it not?

8 **MS RICHARDS:** That's absolutely right. It might be  
9 thought of as a middle-sized centre, perhaps.

10 **SIR BRIAN LANGSTAFF:** Admittedly they may have been rather  
11 less moderate and mild.

12 **MS RICHARDS:** Yes.

13 **SIR BRIAN LANGSTAFF:** But none of those other centres  
14 appear to have had any particular difficulty in  
15 maintaining one commercial product, sometimes two for  
16 the sake of making sure they didn't run out of supply  
17 throughout the whole period, did they?

18 **MS RICHARDS:** Well, it's a mixed picture but that's  
19 certainly true of some centres. There are other  
20 centres where, again, there appear to be multiple  
21 different products being used. Of course, what's  
22 significant, or perhaps of significance here, to bear  
23 in mind is that we're dealing with the treatment of  
24 children.

25 **SIR BRIAN LANGSTAFF:** Yes. But the question is one of

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1 appear to have been possible, at least for periods of  
2 time, for the purposes of study and research to  
3 maintain pupils on a particular concentrate.

4 But other than that, it simply doesn't appear  
5 that there was any attempt to do so at any stage.

6 **SIR BRIAN LANGSTAFF:** And if there was a problem with  
7 commercial supply, you'd expect to see that in the  
8 Winchester purchase orders.

9 **MS RICHARDS:** Yes, or expected to see something which  
10 articulated that as a particular difficulty.

11 **SIR BRIAN LANGSTAFF:** And if it applied to Hampshire,  
12 Winchester, then you'd expect there to be evidence of  
13 that sort of problem affecting other parts of the  
14 country.

15 **MS RICHARDS:** Yes. And although there are from time to  
16 time shortages of particular products we see over the  
17 years, again, there isn't anything, given the whole  
18 stretch of period that we're looking at in relation to  
19 Treloar's, that would suggest that that's an  
20 explanation for the approach that was adopted here.

21 **SIR BRIAN LANGSTAFF:** Well, at the moment it looks as  
22 though the probable conclusion from this, again,  
23 subject of course to what anyone wishes to submit to  
24 me, is that this was a choice made for whatever reason  
25 by the administration at Treloar's, at the centre.

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1 **MS RICHARDS:** Yes.  
 2 And then -- and we can take that down, thank  
 3 you, Soumik.  
 4 As we heard yesterday during the evidence of  
 5 John Peach, you'll recall the letter we looked at from  
 6 Oxford inviting Treloar's to continue to use  
 7 NHS concentrates, to reflect the fact that that's  
 8 what Leigh had been treated with at Oxford.  
 9 And then we saw what in fact happened was  
 10 treatment with multiple concentrates and multiple  
 11 commercial concentrates.  
 12 On a similar theme, there's another example of  
 13 that. If we look at TREL0000175\_090.  
 14 Sir, this another letter from Dr Rizza,  
 15 21 November 1978. It's about different pupils.  
 16 "Thank you for your letter of 10 November about  
 17 the above boys who are interested in learning self  
 18 therapy.  
 19 "I have not seen any of those boys for some time  
 20 now and providing you think they have grown to be  
 21 sensible and responsible individuals, I see no reason  
 22 why they should not go ahead to administer treatment  
 23 themselves."  
 24 "On looking through our records I see that none  
 25 of the boys has Hepatitis B antibody and that they

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1 concentrates but certainly that pattern then  
 2 continued, and there doesn't appear to have been any  
 3 attempt to accede to Dr Rizza's suggestion of adhering  
 4 to NHS concentrate.  
 5 Then moving on from the question of using  
 6 a range of different concentrates to the question of  
 7 how much concentrate overall was used, if we can pick  
 8 matters up in Dr Aronstam's thesis, TREL0000517.  
 9 If we can turn to page 106, we can see, bottom  
 10 of the page, Dr Aronstam says:  
 11 "During the years of the study the amount of  
 12 therapeutic material used [and this is at Treloar's]  
 13 rose by a factor of 2.5 from 561,640 units of  
 14 factor VIII in 1973 to 1,153,340 in 1977 ..."  
 15 Then there's reference to the table showing the  
 16 average weight of haemophiliacs and so on.  
 17 "The annual usage of Factor VIII [this is four  
 18 lines from the bottom of what we see on the screen]  
 19 per bleed has risen from 879 in 1973 to 1045 in 1977,  
 20 a factor of 1.2."  
 21 Then he refers to this increase being sustained  
 22 in the years '77 from '75.  
 23 Then if we look at the next page, the table or  
 24 the first of the tables that was referred to in the  
 25 text is the table we see here, which shows numbers of

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1 have all been treated mainly with NHS factor VIII  
 2 although [then one is identified] has had the  
 3 occasional dose of Armour. I think if possible they  
 4 should receive treatment with the NHS material."  
 5 So a similar request to the request we looked at  
 6 yesterday in relation to Leigh Peach.  
 7 If we then look at TREL0000036\_004.  
 8 This is a document which relates to one of the  
 9 pupils who was the subject of Dr Rizza's letter, and  
 10 although we can see on the first page that the  
 11 treatment is with the Lister material, and likewise on  
 12 the second page, if we look down the bottom of the  
 13 second page we start to see use of Hemofil. And then  
 14 if we go to the next page, what we see is Hemofil and  
 15 then Factorate, and that continues over the page.  
 16 It's then predominantly Hemofil.  
 17 And then if we go to the next page -- these are  
 18 not in date order -- we see Koate and Hemofil.  
 19 If we go to page 7, we can see a range of  
 20 different products -- this is all the same pupil --  
 21 Hemofil, Kryobulin, Koate, Lister.  
 22 If we go on to page 9, Hemofil and Factorate.  
 23 So in fact, I think before that letter from  
 24 Dr Rizza had been written in relation to this pupil in  
 25 any event, the pupil had already been given commercial

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1 patients, and then units of Factor VIII there set out.  
 2 And we can see the increase over the years.  
 3 So an approximate doubling between -- no, not  
 4 a doubling, sorry, an increase between 1973 and 1977  
 5 in terms of the number of patients, from 39 to 51, and  
 6 then proportionately a rather greater increase in  
 7 terms of units of Factor VIII.  
 8 **SIR BRIAN LANGSTAFF:** Yes, it's -- roughly, '77 is one and  
 9 a third times as many patients. It's getting on for  
 10 three times, not quite, the amount of Factor VIII. So  
 11 the individual amounts given has shot up.  
 12 **MS RICHARDS:** Yes.  
 13 Now, it's right to note, if we go to page 112 in  
 14 this document, Dr Aronstam says in the second  
 15 paragraph that:  
 16 "Over the five years of the survey the number of  
 17 bleeding episodes more than doubled."  
 18 Then he says:  
 19 "Treatment policy remained the same, the  
 20 presumption being, therefore, that the haemophiliacs  
 21 entering the College towards the end of the period  
 22 were more severely affected."  
 23 And then at the end of that paragraph he says:  
 24 "The College is probably now only seeing the  
 25 worst cases which cannot be managed at home ..."

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1 If we look at the next page there's  
 2 a description of Dr Aronstam's or the College's  
 3 policy. This is specifically now looking at  
 4 particular types of bleed. If we pick things up --  
 5 well, we can see the second line there:  
 6 "From 15 to 17 years the elbow was the commonest  
 7 site."  
 8 And so on.  
 9 So he's talking about bleeds into the arm, and  
 10 says this:  
 11 "However caused, the increase of bleeding into  
 12 the arm in severely affected adolescent haemophiliacs  
 13 between the ages of 10 and 17 should warrant special  
 14 measures to manage and where possible to prevent these  
 15 bleeds. In response to these findings present policy  
 16 at the College in treating elbow bleeds in pre or  
 17 early adolescence is to ..."  
 18 Then we can see:  
 19 "a) treat these bleeds vigorously."  
 20 That's the articulation of policy, then:  
 21 "b) pay scrupulous attention to restoration of  
 22 function.  
 23 "c) give limited prophylaxis when recurrent  
 24 bleeds occur ..."  
 25 Then:

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1 effects became more and more frequent, culminating in  
 2 the realisation that widespread parenchymal liver  
 3 disease appear to be a direct consequence of  
 4 transfusion therapy. Many other immediate and delayed  
 5 hazards have been described. While no really  
 6 convincing evidence has been presented to link the  
 7 majority of undesirable side effects to the quantity  
 8 of factor VIII transfused, it is logical to look for  
 9 the lowest dose of factor VIII likely to be clinically  
 10 effective."  
 11 So that appears to be an articulation of looking  
 12 at lower dosage. That doesn't appear to be borne out  
 13 by what we see elsewhere, either in terms of the  
 14 approach to individual patients or the overall policy  
 15 which is referred to in other documents as well of  
 16 vigorous treatment and prophylactic treatment.  
 17 **SIR BRIAN LANGSTAFF:** Can you remind me of the phrase  
 18 which he used? I think it is in the file note of the  
 19 meeting with Speywood, which would be IPSN something  
 20 or other, when he said he believed that hepatitis was  
 21 strictly a function of ... and I can't remember the  
 22 last few words.  
 23 **MS RICHARDS:** Yes. It's IPSN0000331\_008. What he says  
 24 there bottom of the page is:  
 25 "... hepatitis is strictly a function of the

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1 "... a programme of physical treatment ..."  
 2 That gives again some insight into what  
 3 Dr Aronstam's approach may have been, one of wanting  
 4 to treat bleeds vigorously.  
 5 If we look at the bottom of the page, he  
 6 identifies the marked increase in the use of  
 7 therapeutic material at the Centre between 1973 and  
 8 '77, and then says:  
 9 "A large part of this can be accounted for by  
 10 the increased bleeding frequency of pupils at the  
 11 College."  
 12 That's the point made on the previous page.  
 13 It's obviously right to point that out. And if we go  
 14 over the page, and we pick it up at the top of the  
 15 page, second line, he says:  
 16 "An increase in the number of transfusions  
 17 rather than the amount of factor VIII per transfusion  
 18 therefore accounts for some of the increased usage of  
 19 factor VIII."  
 20 If we go back to, in the same document, to  
 21 page 86, so this is an earlier part of Dr Aronstam's  
 22 thesis. And he says this, picking it up in the second  
 23 paragraph:  
 24 "As preparations of factor VIII became more  
 25 freely available, so reports of undesirable side

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1 number of doses given ..."  
 2 **SIR BRIAN LANGSTAFF:** The number of doses. So his actual  
 3 view is, if we go back there to where we've just been  
 4 looking at 517\_086, it's 0000517086.  
 5 **MS RICHARDS:** There's no underscore. It's just page 86,  
 6 Soumik.  
 7 **SIR BRIAN LANGSTAFF:** So if one puts the two together, he  
 8 has the view that the number of transfusions creates  
 9 the risk. The amount of each transfusion doesn't  
 10 necessarily but logically it might. That's how they  
 11 reconcile, presumably.  
 12 **MS RICHARDS:** Probably, yes.  
 13 **SIR BRIAN LANGSTAFF:** I mean otherwise they're saying  
 14 different things.  
 15 **MS RICHARDS:** Yes.  
 16 And then -- I'll be coming back to Dr Aronstam's  
 17 thesis in the course of the week, but again, on  
 18 similar themes about the way the Centre treated its  
 19 pupils, if we go to CBLA0003023.  
 20 This is a letter from Dr Stafford, the Devon  
 21 Area Health Authority, Plymouth Health District, to  
 22 Dr Maycock on 21 March 1978. And again it just  
 23 provides a snapshot which may illuminate the approach  
 24 at Treloar's. So it's a patient who has returned to  
 25 the care of Plymouth after leaving Lord Mayor Treloar

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1 what's said to be last year, so presumably 1977.  
 2 What Dr Stafford says to Dr Maycock is this:  
 3 "With this in mind would you please help us.  
 4 Perhaps I might sketch the problem. Treloar had  
 5 a large research grant and were able to give the boys  
 6 740 units of Hemofil every alternate day. As the end  
 7 of his schooldays approached, they told him that this  
 8 form of prophylaxis would cease when he left school  
 9 and, when he came to us on his penultimate holiday, we  
 10 had quite a time trying to reassure him that he would  
 11 cover him. We had no choice, then, to continue the  
 12 Hemofil, since our supplies of Elstree preparations  
 13 were, and are, restricted. After some careful  
 14 negotiating [reference to the parents and The  
 15 Haemophilia Society] ... we cut his dose by half and  
 16 carried him through the latter part of last year with  
 17 a view to switching to Elstree products as soon as our  
 18 reserve stocks allowed us to use four bottles per  
 19 week. This we can now just manage."  
 20 It says in the next paragraph:  
 21 "... we have achieved the switch ..."  
 22 But the patient "still fails to have confidence  
 23 in our surveillance".  
 24 And then it says:  
 25 "We cannot fail to have in mind the financial

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1 paragraph:  
 2 "We have also noted in a recent survey, which is  
 3 awaiting publication, that muscle bleeds on the whole  
 4 require more transfusions per bleed than joint  
 5 bleeds."  
 6 Then this:  
 7 "I am aware that there are many publications  
 8 around at the moment extolling the virtues of lower  
 9 doses of Factor VIII. All I can say, is that I have  
 10 yet to see anything that could be hard data and the  
 11 results must be classed as anecdotal."  
 12 Then he goes on to refer to his own double blind  
 13 controlled trial of three different doses in the  
 14 management of haemarthrosis involving the major  
 15 joints, and again I'll come back to that when we look  
 16 at the research later in the week.  
 17 And then he says further down that paragraph:  
 18 "An interim analysis at this stage of about 100  
 19 elbow bleeds has shown convincing evidence that  
 20 treating elbows with the lower dose results in delayed  
 21 return of full motility (I also think that there is  
 22 accumulating evidence that the low dose is inefficient  
 23 in many other situations)."  
 24 And then he says it's apparent that when the  
 25 elbow is a target joint, the low dose is even more

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1 aspects of this contretemps ... Treloar were running  
 2 at over £20,000 annually, at the current price; we  
 3 were obliged, even with half that, to ask for  
 4 a specific grant from the local DMT to cover this  
 5 boy's therapy ..."

6 And he refers at the end of the letter to having  
 7 written to Dr Aronstam to enter a mild protest at our  
 8 predicament.

9 But then that is an indication, as I say by way  
 10 of snapshot, to two very different approaches to  
 11 treatment: a large amount of treatment by way of  
 12 Hemofil, so commercial concentrate, every alternate  
 13 day on a prophylactic basis at Treloar's; and then  
 14 a much lesser volume given once the patient has  
 15 returned to the home area.

16 Then if we can see a letter from Dr Aronstam  
 17 himself, at TREL0000072\_029, 18 May 1979, to  
 18 Professor Ingram at St Thomas'. This is about  
 19 a different pupil.

20 We can see in the second paragraph Dr Aronstam  
 21 says:

22 "Traditionally at Treloar's, we have used a 20%  
 23 rise for simple, uncomplicated haemarthroses and a 30%  
 24 rise for complicated haemarthroses and muscle bleeds."

25 And he says in the last sentence of the

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1 harmful.

2 Then if we pick it up in the last but one  
 3 paragraph:

4 "As far as the prophylaxis dose is concerned,  
 5 our own studies have shown that a 30% dose for  
 6 prophylaxis is more efficient than the lower dose.  
 7 When using prophylaxis to protect a particular joint,  
 8 I think that a higher dose is always justified.

9 "Finally, I should point out that the  
 10 adolescents in my charge come to me at a greatly  
 11 changing stress on their joint. I believe that I am  
 12 the custodian of these joints during their time with  
 13 me and if I can send them from the College with their  
 14 joints intact, then I believe that I have done some  
 15 part of what I should. Because of this  
 16 responsibility, I think it would be wrong for me to  
 17 use unproven dosage schemes for any length of time."

18 Again, that may provide some insight into  
 19 Dr Aronstam's particular approach into treating  
 20 bleeds.

21 **SIR BRIAN LANGSTAFF:** Is there any indication anywhere in  
 22 how he selected those pupils at Treloar's who will get  
 23 the lesser treatment which he thought would be not  
 24 fulfilling his responsibilities?

25 **MS RICHARDS:** I'm not sure whether there is or not, sir.

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1 Can I check? I'm going to come on to a number of  
2 studies including this one later in the week --  
3 **SIR BRIAN LANGSTAFF:** We'll look at it then perhaps.  
4 **MS RICHARDS:** -- and see if we have that information or  
5 not.

6 Then if we look -- then this goes back to the  
7 question of overall usage of Factor VIII.

8 If we look at HHFT0001073, this is a report in  
9 I think 1986 from the Treloar Haemophilia Centre to  
10 the region. I'm going to come back to a lot of this  
11 report at a later stage when we look more specifically  
12 at the question of the response to AIDS.

13 But if we go to page 6, and we look at the  
14 bottom half of the page, under the heading "Treatment  
15 of Bleeding", Dr Aronstam says this:

16 "The annual use of Factor VIII, which peaked in  
17 1984, has decreased by one-third since then, although  
18 the number of bleeding episodes treated has not  
19 altered significantly. Table 1 also shows very little  
20 change in the total number of transfusions given and  
21 that the number of transfusions per bleed is largely  
22 unchanged. We have, however, significantly reduced  
23 the average amount of Factor VIII given per  
24 transfusion."

25 So this is post-1984, is what he's saying, they

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1 Transfusion Centre. So Dr Zeitlin is the director at  
2 the South London Transfusion Centre in Sutton and he's  
3 writing to Dr Maycock:

4 "Rainsford sent me a copy of his letter to you  
5 of March 18th. When I met him in September of last  
6 year we agreed on the figures which he quotes, and  
7 these have been maintained, with perhaps two  
8 exceptions, when the St Thomas' demands were  
9 exceptionally heavy. More recently Rainsford seems to  
10 have reassessed his position and was asking for the  
11 equivalent of 10,000 cryos a year. This, together  
12 with our other quite heavy commitments, is quite out  
13 of the question, and one wonders what happened to the  
14 Treloar cases before he took over."

15 Then the next paragraph:

16 "Finally, Rainsford feels that 100 bags of cryo  
17 a week is a ridiculous output for the whole region.  
18 In point of fact the whole region (Wessex) is not  
19 producing any!!"

20 That's the perspective of the Transfusion Centre  
21 at that stage supplying Treloar's with its  
22 cryoprecipitate.

23 If we go on a few years to 1974, OXUH0000652,  
24 this is a letter from Dr Aronstam to the Department of  
25 Health and Social Security to Dr Waiter there. And we

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1 have reduced the average amount of Factor VIII given.

2 Then he says:

3 "This is due to a combination of factors.

4 Firstly, our intensive regimes in the early 1980s have  
5 improved joint and muscle states and bleeding episodes  
6 are less severe and less frequent, thus requiring less  
7 Factor VIII. We have also studied the responses to  
8 treatment over the years and have learned the minimum  
9 doses which are needed in different situations."

10 Can I then move to a slightly different topic,  
11 which is just to look at, first of all, mechanics of  
12 supply, and then to look at concerns raised by  
13 Treloar's about shortages of supply.

14 So in terms of mechanics of supply, we looked  
15 earlier this afternoon at that letter in 1969 from  
16 Dr Rainsford to Dr Maycock thanking him for  
17 a provision of an early and emergency supply of  
18 freeze-dried concentrates. And he referred in that  
19 letter to concerns about the limited supply of  
20 cryoprecipitate he'd been receiving.

21 If we just look at a letter from the Dr Zeitlin  
22 referred to in Rainsford's letter. It's at  
23 DHSC0100025\_100.

24 And you'll see it's a letter of 20 March 1969,  
25 National Blood Transfusion Service, South London

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1 can see from this that the source of supply now of  
2 cryoprecipitate is now the Wessex Regional Transfusion  
3 Centre, so no longer looking to receive a product, it  
4 would seem, from South London. It says:

5 "Dear Dr Waiter,

6 "The Treloar Haemophilia Centre is based at the  
7 Lord Mayor Treloar Hospital at Alton and services the  
8 needs of fifty severely affected haemophiliac boys who  
9 reside at the Lord Mayor Treloar College. In  
10 addition, the Centre is responsible for the needs of  
11 all other haemophiliacs in its catchment area, which  
12 is the whole of the North Hampshire Health District.

13 "During 1973 this Centre used 900,000 units of  
14 Factor VIII in the treatment of haemophilia. We used  
15 approximately 650,000 units of Factor VIII as  
16 Cryoprecipitate, 50,000 units as Fresh Frozen Plasma  
17 and about 200,000 units as Human and Animal  
18 Concentrate."

19 So this gives us a snapshot of the picture  
20 before we have the annual returns available from 1976.

21 "Our official supply from the Wessex Regional  
22 Transfusion Centre at Southampton is the equivalent of  
23 10,000 bags of Cryoprecipitate or 182 bags per week  
24 throughout the year. I have been repeatedly told by  
25 Dr Smith that this is the absolute maximum production

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1 he is able to make available for me.  
 2 "The excess material we have used is the  
 3 equivalent of another 77 bags of cryoprecipitate  
 4 a week or 5,000 units of Concentrate per week. I have  
 5 had to obtain these extra materials from a variety of  
 6 sources often at very short notice and at great  
 7 difficulty to both myself and the sources. I have had  
 8 to beg for materials from other transfusion centres:  
 9 from the Lister Institute, from the Oxford Unit; from  
 10 the Bristol and Edgware Transfusion Centres and from  
 11 other Haemophilia Centres who have supplied me with  
 12 material unofficially. I have also had to, when all  
 13 else has failed, buy off the commercial market and  
 14 have spent about £1,000 in the past year.

15 "This situation is quite impossible. We are  
 16 never able to plan ahead and there is always the  
 17 danger that our sources, entirely unofficial, will dry  
 18 up leaving our large pool of haemophilic boys without  
 19 any reserve therapeutic materials for emergencies. At  
 20 a recent Symposium attended by, amongst others,  
 21 Drs Rosemary Biggs and Katharine Dormandy, it was  
 22 agreed that the sort of work we are doing should be  
 23 supported and there should somehow be available  
 24 adequate therapeutic materials for this purpose."

25 Then the top of the next page:

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1 Dr Aronstam.  
 2 There's a discussion now in 1978 about the issue  
 3 relating to supply at page 4, so we can see the  
 4 heading halfway down the page, "Supply of Therapeutic  
 5 Materials", and then if we look at the next paragraph  
 6 down:

7 "Dr Aronstam said that he was encountering  
 8 problems because of the change of policy over ordering  
 9 commercial [Factor] VIII. Initially he had ordered  
 10 the commercial [Factor] VIII on prescription directly  
 11 from the Commercial firms, but now he had to get it  
 12 via his Regional Blood Transfusion Centre and budget  
 13 ahead for how much he would need. He did not think  
 14 that he would be able to manage within his budget."

15 Then:

16 "Dr Smith [who I think was the Director of the  
 17 Wessex Transfusion Centre] said that he did not think  
 18 that there was any problem in the Wessex Region apart  
 19 from the one at Alton, which was a special case  
 20 because of the large number of haemophilic boys at the  
 21 College. He was awaiting the DHSS's reply to a  
 22 request for official recognition of the special  
 23 situation at Alton."

24 Then if we skip down two paragraphs, it then  
 25 says:

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1 "I have calculated that, on the commercial  
 2 market, our shortfall of Factor VIII would cost  
 3 £26,000 annually. I feel it imperative that our  
 4 supplies are guaranteed, especially as we are looking  
 5 after boys from all over the country and may therefore  
 6 be quite reasonably be regarded as providing  
 7 a national service. I should like to appeal to you to  
 8 make the necessary funds available so that, until  
 9 a guaranteed supply can be made available from within  
 10 the Health Service, we are able to buy all our needs  
 11 on the commercial market."

12 So you will see that's Dr Aronstam's stance as  
 13 at 1974. Clearly wanting to maintain what he regarded  
 14 as the necessary supply for the treatment of the  
 15 pupils at Treloar's and indeed for the treatment of  
 16 the haemophiliacs in the wider catchment area.

17 So we can see at that point in time it would  
 18 appear that Dr Aronstam was able to make his own  
 19 purchases of commercial products, but his request was  
 20 for enhanced funding.

21 If we look then at OXUH0003765\_020, we can see  
 22 that these are the "Minutes of Haemophilia Centre  
 23 Directors and Blood Transfusion Directors within the  
 24 Oxford Haemophilia Supraregion ... 19th June, 1978",  
 25 and the second attendee down is identified as being

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1 "The question was raised as to whether or not  
 2 Alton should send a bill to the other regions for the  
 3 [Factor] VIII used by boys at the College. This was  
 4 discussed but thought difficult as the NHS did not  
 5 like to do cross-accounting and it would prove very  
 6 difficult to organise this for Alton in isolation.

7 "There was a strong feeling amongst the  
 8 Directors that the DHSS be reminded of the continuing  
 9 shortage of NHS freeze-dried factor VIII and of the  
 10 continuing need to buy commercial factor VIII."

11 So that's the discussion in 1978. Then if we  
 12 just go back, I'm going to slightly earlier in the  
 13 1970s.

14 There's a letter from Dr Aronstam, PRSE0002515.

15 This is looking at shortages on a national  
 16 scale, and what he viewed as under-treatment,  
 17 effectively, or insufficient treatment being therefore  
 18 possible on a national scale and not simply looking at  
 19 the position of Lord Mayor Treloar College, although  
 20 he refers to it in his letter.

21 So it's a letter from Dr Aronstam -- I'm so  
 22 sorry. It's a letter from Dr Biggs -- my apologies --  
 23 to The Lancet, June 29, 1974, about the national  
 24 picture.

25 Then if we pick up the reference, bottom half of

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1 the page, to Treloar's. We can see it's about ten  
2 lines up from the bottom. It says:  
3 "Even with dire economy, some centres have been  
4 hard pressed to maintain minimum treatment. For  
5 example, the treatment of the boys at the Lord Mayor  
6 Treloar College at Alton in recent years has been  
7 maintained against a background of begging and  
8 borrowing from other centres from one week to the  
9 next. Were the school not supplemented in this way,  
10 it is calculated that there would be a deficit of  
11 about 260,000 factor VIII units annually."

12 So it -- contrary to what one might think is the  
13 picture which emerges from other documents including  
14 the returns, which appears to show very substantial  
15 volumes of concentrates being used, the perspective of  
16 Dr Aronstam apparently shared by Dr Biggs and perhaps  
17 some of the other Directors does appear to be that  
18 there is insufficiency for Treloar's to perhaps treat  
19 pupils as much as it would like.

20 Then the letter from Dr Biggs continues with an  
21 overall expression of concern about what's said to be  
22 insufficiency of NHS product and, therefore, the need  
23 to supplement that by reference to the purchase of  
24 commercial products.

25 If we then go to DHSC0100005\_159, this is a --

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1 in time at the Royal Free.

2 But significantly more, by way of example,  
3 than -- or some more than it seems to be anticipated  
4 for use at large centres such as Manchester Royal  
5 Infirmary.

6 And then there's another letter -- sorry, I'll  
7 find it in a moment -- at CBLA0000219.

8 This appears to be an example of what was  
9 described as the begging and borrowing. So this  
10 a July '74 letter from Dr Aronstam to Dr Maycock.

11 "Thank you for your letter offering to provide  
12 five bottles of this material per week. As you know,  
13 this is not the answer but it is certainly a help and  
14 I would be very grateful for this to be instituted as  
15 soon as possible.

16 "May I take it that I can still try to obtain  
17 more as dire needs arise?"

18 If we look, however, at CBLA0000745, we get  
19 a slightly different picture here. So this is  
20 March '78, Dr Aronstam to Dr Stafford. Again, it's in  
21 the context of an individual patient but it's the  
22 wider points being made by Dr Aronstam that are of  
23 interest.

24 Picking it up in the second sentence of the  
25 second paragraph:

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1 sorry, go to the second page.

2 This, again, looks at the picture in the early  
3 part of the 1970s, so it's:

4 "Anti-haemophilic Factor Issues 1970-74 ...  
5 Principal Users."

6 We can see it gives a pattern of usage from 1970  
7 through to the first half of 1974, and figures for  
8 a number of centres.

9 We can just pick up the picture in relation to  
10 Treloar at the bottom of the table. So we can see the  
11 figure there given, 38, then 34, 66, and then by 1973,  
12 497, and then the 504 for January to June is not to be  
13 doubled, but is representative of what's said to be,  
14 extrapolating, likely to be the annual usage for that  
15 year.

16 So, again, for that period when we don't have  
17 the annual returns, it appears to show a significant  
18 increase in terms of product usage in that first part  
19 of the 1970s.

20 And if we just go back to the whole table, we  
21 can see, for example, Treloar's comparing very  
22 similarly to the Royal Free in terms of what's  
23 anticipated for 1974. The Royal Free are a much  
24 larger centre, albeit I don't think we have figures  
25 for the number of severe haemophiliacs at that point

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1 "You may be interested to hear that we now use  
2 prophylaxis routinely in many clinical situations, and  
3 we feel that it can be of positive benefit when some  
4 of our boys are going through difficult patches.

5 "We are obviously more fortunate than you in  
6 that the Wessex Region is supplying us with all  
7 material we need for our admittedly enthusiastic  
8 programme. The climate with regard to prophylaxis  
9 appears to be changing and I do hope the wind of  
10 change blows your way fairly soon."

11 As well as putting perhaps a slightly different  
12 complexion, at least by 1978, on the concerns  
13 expressed earlier in the seventies on the issue of  
14 supply, it may reflect the possibility that it's the  
15 enthusiastic programme, to use Dr Aronstam's own term,  
16 and the use of prophylaxis which may be leading to  
17 Dr Aronstam, or the Centre more broadly, at various  
18 stages saying, "We don't have enough, we need more."

19 If we then look at a letter the following year,  
20 again, it perhaps gives yet a different perspective.

21 It's HHFT0001062.

22 Here we have Dr Aronstam writing on  
23 19 November 1979 to the regional medical officer in  
24 Winchester, expressing difficulties in terms of  
25 getting sufficient resources. So it says:

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1 "Following our conversation last week I have  
 2 been looking into ways of conserving resources.  
 3 I have explored several avenues with mixed success:  
 4 "1) I have attempted to switch to the cheaper  
 5 brands of commercial concentrate, but have been  
 6 frustrated because the transfusion service has bought  
 7 its stocks up to the end of the financial year and no  
 8 amount of switching on my part will save any money.  
 9 "2) I have approached my biggest supplier of  
 10 concentrate and asked them to cut their price. They  
 11 have responded by offering a certain amount of free  
 12 material over the next few months, but for the reasons  
 13 mentioned above, this again will not save any actual  
 14 hard cash.  
 15 "3) I have asked BTS to supply me with more NHS  
 16 cryoprecipitate which would save money on commercial  
 17 concentrate, but is much less convenient for us to  
 18 use. However, I have been frustrated in this too  
 19 because of a Regional directive to send more plasma to  
 20 the Lister Institute to make NHS concentrate and there  
 21 is, therefore, less available for locally produced  
 22 cryoprecipitate. This double squeeze is perhaps not  
 23 appreciated by yourself, but the two aims of a) using  
 24 more cryoprecipitate and b) sending more plasma to the  
 25 Lister Institute are not compatible.

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1 possible options and how you feel I can still save  
 2 money if all the above measures fail."  
 3 So again, provide some insight into  
 4 Dr Aronstam's thinking at the end of the 1970s,  
 5 although perhaps not very easy to reconcile with his  
 6 March '78 letter talking about being able to get all  
 7 the material they need for their admittedly  
 8 enthusiastic programme.  
 9 Sir, I note the time. We started late, but I'm  
 10 conscious I've been going for an hour and five  
 11 minutes, and I'm proposing to do a little more today,  
 12 but it may be that others would benefit from a break.  
 13 **SIR BRIAN LANGSTAFF:** Yes, well we'll take a break in that  
 14 case until 4 o'clock.  
 15 **(3.35 pm)**  
 16 **(A short break)**  
 17 **(4.02 pm)**  
 18 **SIR BRIAN LANGSTAFF:** Yes?  
 19 **MS RICHARDS:** Sir, there's just another four or five  
 20 documents on the topic of supplies, mechanics of  
 21 supply and shortages to look at before looking at some  
 22 documents relevant to the question of prophylaxis.  
 23 DHSC0002197\_084 please, Soumik.  
 24 This is a letter written by Dr Aronstam dated  
 25 18 April 1980 to the British Medical Journal, and it's

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1 "4) ..."  
 2 "And then this refers back to the double blind  
 3 controlled trial:  
 4 "... We have recently complete a double-blind  
 5 controlled trial in the treatment of hemarthrosis and  
 6 I am able to from this work halve the dose of  
 7 factor VIII which we are giving for ankle bleeds. In  
 8 the long term this should result in substantial  
 9 savings."  
 10 And he refers to a paper.  
 11 "5) I have, in addition, enjoined the College  
 12 academic staff to institute more severe discipline in  
 13 the hope that spontaneous bleeds may be reduced in  
 14 frequency. This goes very much against my views on  
 15 the management of haemophilia and I am bitterly  
 16 disappointed at having to resort to these measures.  
 17 In response to my appeal the headmaster is sending out  
 18 the enclosed letter to all parents."  
 19 And obviously I can ask the headmaster about  
 20 that tomorrow.  
 21 "6) Finally, the only other option left is to  
 22 under treat the boys. This I am in no circumstances  
 23 prepared to do and if all else fails and your mention  
 24 of curtailing on admission to the College would still  
 25 come about, I would like you to put in writing the

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1 on the topic of supply. It says:  
 2 "Dear Sir,  
 3 "re: Factor VIII Supply and Demand  
 4 "Both Biggs and Cash have estimated the  
 5 requirements of factor VIII in the United Kingdom to  
 6 be around 50,000,000 units per annum. Both these  
 7 authorities have based their calculations on the  
 8 annual usage of factor VIII up to and including 1975.  
 9 For reasons documented below, I believe this figure to  
 10 be now a very serious underestimate of future  
 11 requirements ..."  
 12 Then he gives his reasons:  
 13 "(a) An explosive growth in prophylaxis  
 14 (negligible in 1975 in the United Kingdom) has taken  
 15 place from 1976. The use of prophylaxis has been  
 16 shown to substantially increase the usage of  
 17 factor VIII, two to four times the amount of  
 18 factor VIII in current use being required for  
 19 a prophylactic programme.  
 20 "(b) The number of patients on home therapy in  
 21 the United Kingdom increased by one third in 1976.  
 22 Rizza has shown that patients on home therapy use 15%  
 23 more factor VIII than those on hospital-based  
 24 treatment. This increase in material usage may be  
 25 balanced out by the trend to lower dosages for early

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1 bleeds treated at home. However, the 15% failure rate  
2 at low dosage which is not very different from the  
3 retransfusion rates for boys at Lord Mayor Treloar  
4 College, cannot be ignored. As the majority of bleeds  
5 occur into the knees, elbows and ankles, it is  
6 disturbing to contemplate the effect of lowering the  
7 dose of factor VIII still further in the 15-20% of  
8 joint bleeds which would have failed to respond even  
9 to standard dosage."

10 Then his point (c) refers to lengthening  
11 lifespan:

12 "The lengthening of haemophilic life-span is  
13 likely to lead to a doubling of the haemophilic  
14 population."

15 Point:

16 "(d) It is self evident that most haemophiliacs  
17 who were able to produce children in the past were  
18 likely to have been suffering from milder forms of the  
19 disease. Because the severity of the disease breeds  
20 true in families an improvement in survival and  
21 therefore of a reproductive capacity is likely to bias  
22 the haemophilic population to the severer forms. As  
23 the severest 20% of the haemophilic population use  
24 80% of the blood resources, this will have  
25 a considerable impact on demand of factor VIII in the

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1 attempt to avert this approaching crisis. As it is  
2 apparent that the National Health Service facilities  
3 are incapable of processing enough of the voluntary  
4 donations from this country, surely we should explore  
5 the possibility of commercially successful private  
6 industries fractionating the material for the National  
7 Health Service. This approach would provide a glimmer  
8 of hope in what otherwise seems a very gloomy  
9 prospect."

10 As well as writing in those terms to the British  
11 Medical Journal --

12 **SIR BRIAN LANGSTAFF:** Was this published?

13 **MS RICHARDS:** Ah, do you know, I think it was, or his  
14 expectation was that it was. But we have it in this  
15 form, and I'll have to check.

16 But if we look at DHSC0002197\_083, we can see on  
17 30 April that Dr Aronstam wrote to Patrick Jenkin,  
18 Minister for Health and Social Security saying:

19 "I enclose a copy of a letter awaiting  
20 publication in the British Medical Journal. I think  
21 you may not be aware of the facts presented and  
22 possibly not of the commercial alternative to  
23 a therapeutic disaster."

24 And that is presumably a reference to what he  
25 says at the end of the letter about the possibility of

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1 future."

2 Point (e) relates to the treatment of patients  
3 with inhibitors and he refers to:

4 "Patients with low inhibitors levels and low  
5 antibody response to treatment with factor VIII are  
6 now treated with high doses of factor VIII for almost  
7 all bleeds."

8 So those are the reasons that he identifies for  
9 considering that the Biggs and Cash estimate is a very  
10 serious underestimate.

11 Then he says this:

12 "It is apparent from my own experience that the  
13 National Health Service cannot provide more than  
14 a fraction of my needs for the treatment of 70 severe  
15 haemophiliacs. The shortfall is made up by the  
16 purchase of expensive commercial concentrates and it  
17 has been made plain to me that there will be pressures  
18 to cut the amount made available and in the  
19 foreseeable future no prospect of any increase. If  
20 this situation is reflected nationwide, and I have no  
21 reason to believe that it is not, then the escalating  
22 requirement must shortly overtake the diminishing  
23 resources and create a major crisis in the  
24 expectations for haemophilia treatment.

25 "I think it is essential that we recognise and

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1 asking commercial private industry to fractionate NHS  
2 material.

3 There was certainly a letter published in the  
4 BMJ from Dr Aronstam in September 1980. I'll need to  
5 compare the text. It's on the same theme but whether  
6 it was identical in text I'll need to check.

7 We know that because Dr Biggs -- I'm sorry,  
8 Dr Bidwell wrote to Dr Aronstam in response in  
9 October 1980, taking issue with some of what he'd  
10 said, but I just want to pick up then on Dr Aronstam's  
11 own letter back to Dr Bidwell because our concern  
12 today is to learn more about the approach at Treloar's  
13 and, in particular, the approach of Dr Aronstam.

14 That's at CBLA0001199.

15 It's a letter of 10 November 1980 in response to  
16 Dr Bidwell's letter of 29 October, and you'll see she  
17 had used in her response phrases such as  
18 "ill-informed" and "half-truths", but I want to pick  
19 up what is said in the last paragraph:

20 "My main concern [says Dr Aronstam] is the  
21 provision of sufficient factor VIII for the adequate  
22 treatment of my patients and I remain concerned that  
23 there is still no prospect in sight of the National  
24 Health Service being able to provide me with  
25 sufficient factor VIII. I remain dependent on the

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1 purchase of expensive commercial concentrate much  
2 against my will."

3 Is what Dr Aronstam there said.

4 And then we've looked previously, I won't go  
5 back to the document itself, at the UKHCDO meeting in  
6 September 1980, at which there was a discussion about  
7 the switch to the pro rata system of returns in terms  
8 of what would be made available to the Haemophilia  
9 Centre would depend upon what the local Blood  
10 Transfusion Centre was able to send to BPL. But there  
11 was a specific discussion that then followed about  
12 what would happen for the Wessex region because of  
13 Lord Mayor Treloar's -- what was said to be its  
14 special position.

15 If we can go to CBLA0001294, this is a document  
16 we looked at in part during the presentation on the  
17 Belfast Haemophilia Centre because it contained  
18 a discussion of the position in relation to Northern  
19 Ireland. So it's a report for the advisory committee  
20 on the National Blood Transfusion Service, and it's  
21 a report, internal Department of Health report,  
22 February 1981. We'll see the heading is:

23 "Pro rata Distribution of Blood Products", and  
24 paragraph 1 says:

25 "As Members know, from 1 April 1981 it is

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1 per annum for use in approximately 1,800 severe  
2 haemophiliacs. Therefore a special allocation could  
3 be made to the Wessex RHA (in addition to that due  
4 under the pro rata distribution) of 7,500 [units] per  
5 pupil. This figure could be reviewed annually to take  
6 into account BPL's increasing production and changes  
7 in the number of pupils in the Hospital. As  
8 Appendix 1 shows under a strict application of pro  
9 rata, Wessex [Regional Health Authority] would lose  
10 approximately 288,000 [units] per annum. This system  
11 would 'restore' 300,000 [units] to the region. Such  
12 an allocation could be accommodated within the 20%  
13 figure described above.

14 "7. The Secretariat acknowledges that this is  
15 very much a 'rough and ready' assessment. However, a  
16 more sophisticated basis of calculation, e.g. one  
17 based on individual patients' needs or a system which  
18 sought to take into account individual arrivals and  
19 departures could place an additional administrative  
20 burden upon BPL at a time when the pro rata system  
21 itself will inevitably add to the Laboratory's  
22 workload. There could also be difficulties in  
23 defining patients' 'normal residence' when, as  
24 sometimes happens, a patient's family moves to Wessex  
25 to be closer to the Hospital."

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1 intended to introduce a system of pro rata  
2 distribution of certain blood products to ensure that  
3 [Regional Health Authorities] receive such products in  
4 proportion to the quantity and quality of plasma sent  
5 to ... (BPL) for fractionation."

6 So that was the general scheme. But if we go to  
7 the second page, we can then see the specific  
8 discussion in relation to how that scheme might apply  
9 in Wessex. So if we zoom in at the top half of the  
10 page -- thank you -- paragraph 5:

11 "Each RHA [Regional Health Authority] has at  
12 least one Haemophilia Centre. However, Wessex RHA  
13 faces a special problem regarding its level of  
14 Factor VIII usage because of the Lord Mayor Treloar  
15 Hospital. The Hospital might be more accurately  
16 described as a residential school and its pupils (40),  
17 all of whom are severe haemophiliacs, are drawn from  
18 all over the country.

19 "6. Any system of special allocations must be  
20 kept as simple as possible to avoid additional work  
21 for BPL. One possible method of calculating such an  
22 allocation for the Lord Mayor Treloar would be on the  
23 following lines ..."

24 Then we can see what's set out.

25 "BPL produces 14 million [units] of Factor VIII

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1 Then if we look at the third page we can see,  
2 towards the top of the page, under the heading,  
3 "Summary", paragraph 10, that:

4 "The Committee's views are sought on ..."

5 And then a number of questions, but the first of  
6 which was:

7 "a. whether a special allocation should be made  
8 to Wessex RHA because of the Lord Mayor Treloar  
9 Hospital ..."

10 And:

11 "b. If so, how might that ... be assessed ..."

12 And in terms of the decision that was made, we  
13 can see it briefly referred to, we haven't got all the  
14 underlying documents available today but if we just  
15 look at CBLA0001341, we can see in this letter from  
16 Dr Lane to the DHSS dated 24 April 1981, it says:

17 "I believe it is now agreed that the only  
18 special provisions for factor VIII distribution are as  
19 follows ..."

20 And the first there is the Lord Mayor Treloar  
21 College. So the decision to have a special allocation  
22 was thus approved.

23 The final topic on the question or, as it were,  
24 under the heading of blood product usage and  
25 approaches to treatment, is just to look a little bit

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1 more at the question of prophylaxis.  
 2 Sir, we have seen in the oral evidence that  
 3 we've heard this week various references to  
 4 prophylactic treatment, and what we've seen this week  
 5 is, as far as we can ascertain, pretty representative  
 6 in terms of the approach to prophylaxis generally for  
 7 other Treloar's pupils. So we've looked at the  
 8 records, thousands of pages of documents, ultimately  
 9 in terms of individual medical records of pupils at  
 10 Treloar's, and we see prophylaxis, prophylactic  
 11 treatment, as a regular feature of the treatment of  
 12 the pupils at Treloar's.

13 Sir, I'm not going to go back then to any of the  
 14 individual witness statements, but we've referred to  
 15 a number of individual statements in our written note,  
 16 in addition to those from whom we've heard orally,  
 17 which discuss the use of prophylactic treatment, on an  
 18 individual basis.

19 There's just a handful of further documents  
 20 which again perhaps just throw a little further light  
 21 on Treloar's approach to prophylaxis.

22 If we look at TREL0000332\_068.

23 Sir, this is a letter from Dr Aronstam,  
 24 14 November 1978. It's to Professor Lee at St Mary's  
 25 Hospital, Portsmouth. Again, it's in the context of

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1 trials from this Centre. What I am also becoming  
 2 increasingly aware of is the potential danger to our  
 3 haemophiliac population of hypertransfusion with blood  
 4 products. Over the past year only 12 of our 55 boys  
 5 have had liver function tests which remained normal.  
 6 Several authorities have recently reported increased  
 7 incidences of chronic aggressive hepatitis. There is  
 8 also accumulating evidence that the haemophiliac  
 9 population has a higher blood pressure than the normal  
 10 population and our observations here suggest that this  
 11 may also be related to frequency of transfusions."

12 Then there's a reference again to the individual  
 13 patient.

14 "I am therefore increasingly wary of the  
 15 indiscriminate use of blood products in our boys.  
 16 This does not mean that I do not use prophylaxis in  
 17 certain situations. I believe that the clinical  
 18 indications for prophylaxis are ..."

19 Then we can see three indications given:  
 20 "...frequency of bleeding. By this I'm talking  
 21 about 20-30 bleeds per hundred days."

22 Sorry, can we take this document down. There's  
 23 a name that's not been redacted. I'm just going to  
 24 read the relevant parts of the remainder of this  
 25 letter if I may.

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1 a specific patient, and this is not a current  
 2 Treloar's patient. We can ascertain that from the  
 3 date of birth we see at the top. 1959 is probably not  
 4 a current Treloar's patient.

5 But again, there's a general insight into  
 6 Dr Aronstam's views on prophylaxis. Sir, we can see  
 7 at (a) Dr Aronstam says:

8 "I undertake the clinical responsibility for 55  
 9 of Britain's severest haemophiliacs for thirty-six  
 10 weeks of the year. There is no way I would be  
 11 prepared to take on this commitment without the  
 12 freedom to make my own clinical decisions."

13 Then there's reference to a particular  
 14 conversation held with Professor Lee's registrar.  
 15 I don't think we need to go into that.

16 He says in the next paragraph:

17 "I should point out that my patients come from  
 18 many sources, and have been managed in many different  
 19 ways - some good, and some bad. I try to have  
 20 a consistent approach to treatment here, which means  
 21 that I occasionally use a different approach to that  
 22 of the Home Centre.

23 "(b) As far as prophylaxis itself goes, I am  
 24 well aware of its potential for reducing the frequency  
 25 of bleeding episodes, having published two controlled

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1 Dr Aronstam says:

2 "I believe the clinical indications for  
 3 prophylaxis are 1) frequency of bleeding, 2) the  
 4 covering of a bad patch, 3) cover for an extended  
 5 course of physiotherapy and for invasive procedures."

6 Then he says:

7 "I do not believe in extended prophylaxis in any  
 8 other situation."

9 There is then a discussion about the treatment  
 10 of the individual patient again, and then, at the  
 11 bottom of the second page, just for your note, sir,  
 12 when you look at the document again, Dr Aronstam  
 13 refers to available resources of Factor VIII, and  
 14 says:

15 "This country is not sufficient in Factor VIII  
 16 and even if I believed that prophylaxis was always the  
 17 right management for all haemophiliacs, we are still  
 18 in the position of rationing this form of treatment.  
 19 It is up to all of us to allocate resources  
 20 responsibly and as we see fit."

21 Then his next point in the letter is headed:

22 "The influence of different environments", and  
 23 Dr Aronstam says this:

24 "The situation at Treloar College currently is  
 25 that treatment is immediately available and our boys

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1 are almost bullied into the early reporting of bleeds.  
 2 Consequently, they lose minimal time from school  
 3 compared to ..."  
 4 Then he compares it to the situation of those  
 5 having to be admitted elsewhere.  
 6 Then he says at the end of the letter:  
 7 "From our extensive experience of prophylaxis,  
 8 I can assure you that unless combined with an active  
 9 course of physiotherapy, prophylaxis does not improve  
 10 either joint function or the underlying bleeding  
 11 frequency."  
 12 Sir, we can see there -- sorry, November 1978 --  
 13 Dr Aronstam, as it were, expressing some  
 14 qualifications or limitations on the use of  
 15 prophylaxis.  
 16 Then again, just to try to get an insight into  
 17 his overall approach to prophylaxis, if we look at  
 18 TREL0000108\_016, again, this is a letter -- this is  
 19 16 January 1980. This, I think, is a letter to  
 20 a parent. But if we just pick it up in the second  
 21 paragraph, third line, Dr Aronstam says:  
 22 "We only give prophylaxis in short courses here  
 23 and only when a particular joint is being threatened.  
 24 I am afraid we do not have the resources to give any  
 25 of our 55 severe haemophiliac boys a long course of

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1 the only way to try to ascertain what his approach  
 2 might have been and what the significance of that  
 3 might then have been in turn for what happened at  
 4 Treloar's is to look at what he says at various times  
 5 to various different people.  
 6 There is also a section on prophylaxis in his  
 7 thesis but I'm going to come on to that again when  
 8 I look at research, which will be on I think Friday of  
 9 this week.  
 10 Then a document that I think is probably  
 11 consistent with the oral evidence we have heard but if  
 12 we just look at it, TREL0000075\_100, this is a letter  
 13 to Dr Hann, Great Ormond Street, July 1978. Again,  
 14 the first paragraph is concerned with the individual  
 15 patient, but if we pick it up in the second paragraph,  
 16 he says:  
 17 "In our experience prophylaxis is much more  
 18 effective given on alternate days than twice weekly.  
 19 If he is now under your care and you wish him to  
 20 continue with prophylaxis while with us, we will need  
 21 to resolve the frequency and I would be grateful if  
 22 you could let me have your views on this."  
 23 Written confirmation there of what we have heard  
 24 orally was the experience of some of the pupils, that  
 25 when they were on courses of prophylaxis, it intended

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1 prophylaxis just because of bleeding frequency. You  
 2 will realise that it all costs a lot of money and the  
 3 National Health Service just does not have that sort  
 4 of money at the moment. Please rest assured however  
 5 that if at any time I feel that your boys warrant a  
 6 short course of prophylaxis they will certainly get  
 7 it."  
 8 **SIR BRIAN LANGSTAFF:** The view expressed there in  
 9 January 1980 compares with his indications for  
 10 treatment just over a year earlier, which appeared to  
 11 indicate that the indication for prophylaxis was 20 to  
 12 30 bleeds in every hundred days, which would suggest  
 13 long term prophylaxis, so they don't fit, do they?  
 14 **MS RICHARDS:** No. And, sir, the purpose of going to these  
 15 documents is really to map out what appears to be  
 16 a degree of inconsistency, or at least tension, in  
 17 what is said by Dr Aronstam at different times, both  
 18 in terms of availability of supplies and in terms of  
 19 the approach to prophylactic treatment.  
 20 **SIR BRIAN LANGSTAFF:** I mean, he is entitled to change his  
 21 views.  
 22 **MS RICHARDS:** Absolutely.  
 23 **SIR BRIAN LANGSTAFF:** But it's not obvious at what stage  
 24 and on what basis.  
 25 **MS RICHARDS:** No, and we obviously can't ask him. And so

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1 to be on an alternate day basis.  
 2 There's then just, I think, a couple of letters  
 3 which indicate that the use of factor concentrates on  
 4 a prophylactic basis continued into 1983 and 1984, so  
 5 we've been looking at documents largely from the  
 6 seventies and 1980.  
 7 But if we look at TREL0000343\_044, so this is  
 8 a letter from Dr Aronstam, 19 March 1984. It's  
 9 concerning a child. We can tell that it's addressed  
 10 to a consultant paediatrician, and it's a relatively  
 11 young child, I can indicate that much.  
 12 Then there's a discussion in the last paragraph,  
 13 sorry, in the second paragraph, first of all, there's  
 14 a discussion about prophylaxis, where Dr Aronstam  
 15 says:  
 16 "I am sure that the correct approach is a course  
 17 of effective prophylaxis."  
 18 And there:  
 19 "I think the only guidelines to the correct  
 20 regime are to titrate the results against the dose.  
 21 If there is breakthrough bleeding, then it is  
 22 necessary to increase the dose and/or frequency of  
 23 infusion. On his present regime it appears that the  
 24 major problems occur on Sundays and certainly in my  
 25 own experience I have found an alternate day regime

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1 preferable to a fixed three times weekly schedule."  
 2 So there is a view expressed in March 1984 about  
 3 using prophylaxis for this child. And it's just --  
 4 note that set against what we see in the last  
 5 paragraph of the letter.  
 6 "I note your comment about factor VIII  
 7 preparations affecting 'T' cells. This is a very  
 8 worrying problem for all of us in haemophilia care.  
 9 At present, the general view is that while the disease  
 10 is horrific, the numerical risk of it is nevertheless  
 11 very small and should not deflect us from the  
 12 appropriate treatment. Naturally we are all reviewing  
 13 the situation constantly."  
 14 Now, the reference to the disease that is  
 15 horrific must, I think, be a reference to AIDS.  
 16 That's the only inference that makes sense. This  
 17 might tend to suggest that Dr Aronstam's approach to  
 18 the use of prophylaxis has not changed at all, at  
 19 least as at March 1984, by what else was happening in  
 20 terms of the knowledge of risk of AIDS.  
 21 Then if we just move to the end of 1984,  
 22 TREL0000247\_007, this is a letter to Dr French at the  
 23 Haemophilia Centre in Nottingham, 14 December 1984.  
 24 Again, about a different patient.  
 25 And we can see if we look at the third

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1 So the same approach again appearing to be taken  
 2 to the use of prophylaxis at the very tail end of 1984  
 3 with everything that was otherwise known at that point  
 4 in time.  
 5 Then the last document on the issue of  
 6 prophylaxis is at TREL0000092\_132.  
 7 This takes us into July 1987. We can see from  
 8 the second main paragraph that there is still a 20%  
 9 alternate day prophylaxis programme being undertaken  
 10 in 1987. Again, this is in relation to a different  
 11 patient again.  
 12 But we can then see what Dr Aronstam says --  
 13 sorry, it's Dr Wassef says in the next paragraph:  
 14 "He has done very well in the past two months  
 15 while on prophylaxis. The decision to terminate his  
 16 prophylaxis was taken after careful consideration  
 17 because of the recent increase in the number of  
 18 published papers about the immuno-suppressive effects  
 19 of Factor VIII concentrate, particularly in anti-HIV  
 20 positive haemophiliacs."  
 21 Then he goes on to talk about having stopped the  
 22 prophylaxis and giving the patient a rest.  
 23 So we can see there termination of  
 24 a prophylactic programme there because of what's said  
 25 to be the risks of Factor VIII concentrate but there's

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1 paragraph, reference there to the prophylactic  
 2 programme. It says -- sorry, can I pick it up in the  
 3 previous paragraph. My fault.  
 4 "He has been on prophylaxis for almost the whole  
 5 length of this term."  
 6 So this is the autumn term of 1984 it must be,  
 7 because the letter is being written in mid-December  
 8 '84.  
 9 "Having [broken] through the 20% raise alternate  
 10 day prophylactic barrier, he likewise did with the 30%  
 11 alternate day and consequently we started him on 15%  
 12 raise daily in an attempt to decrease the frequency of  
 13 bleeds into his elbow. His daily prophylaxis was  
 14 stopped on 19.11.84 because of the changeover to  
 15 heat-treated factor VIII. In the following week he  
 16 bled four times into his elbow, before his 20% heat  
 17 treated Factorate prophylaxis was resumed on  
 18 27.11.84."  
 19 So we can I think infer from that that this  
 20 program of prophylaxis for almost the whole term in  
 21 the autumn of 1984 continued until what we've seen  
 22 there is the date of 19 November on unheated  
 23 concentrates, and then there was a switch to at the  
 24 end of November prophylaxis was resumed, this time  
 25 using heat-treated Factorate.

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1 no indication at any earlier stage in the documents  
 2 we've seen of prophylaxis coming to an end because of  
 3 the potential risks involved.  
 4 Sir, the last topic I'm going to cover today, it  
 5 just looks at the involvement of Treloar's clinicians  
 6 in UKHCDO. I'm going to do that to lay the groundwork  
 7 then for an exploration of what the documents show us  
 8 about knowledge of risk on the part of Treloar's  
 9 clinicians in relation to hepatitis and HIV, which  
 10 I'll come on to tomorrow afternoon.  
 11 We can just see from a number of documents that  
 12 clinicians at Treloar's really were very closely  
 13 involved with UKHCDO and UKHCDO meetings.  
 14 Dr Rainsford attended the 1968 Haemophilia  
 15 Centre Directors meeting. If we just look briefly at  
 16 HCDO0001013, we can see there it's the minutes of the  
 17 meeting of Haemophilia Centre Directors held at the  
 18 Oxford Haemophilia Centre 1st October 1968. And if we  
 19 look down the list of attendees, which helpfully is in  
 20 alphabetical order, towards the bottom we can see:  
 21 "Dr SG Rainsford, Lord Mayor Treloar College."  
 22 I'm not going to go into the detail of what was  
 23 discussed at each and every one of these meetings but  
 24 Dr Rainsford was thereafter a fairly regular attendee.  
 25 Dr Aronstam was a regular attendee from

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1 April 1971 and, again, if we just look briefly at  
2 that, HCDO0001014, we can see this is the meeting of  
3 5 April 1971. And if we go down the page and the list  
4 of attendees, we can see Dr Rainsford is there  
5 identified as attending and Dr Aronstam. They're  
6 recorded as representing at that point Alton General  
7 Hospital.

8 In terms of attendance, I'm not going to go to  
9 the documents but I'm just going to give a list of the  
10 meetings and who attended when in the course of the  
11 1970s and early '80s.

12 Sir, the 27 October 1972 meeting was attended by  
13 Dr Arblaster, Dr Aronstam and Dr Rainsford. The  
14 November '74 meeting was attended by Dr Rainsford and  
15 Dr Arblaster. The September '75 meeting was attended  
16 by Dr Aronstam and Dr Rainsford. And although Dr Kirk  
17 is not listed in the list of attendees, it's clear  
18 from the minutes of the meeting that Dr Kirk was there  
19 too.

20 Sorry, I've missed 1974. That was a joint  
21 meeting with blood transfusion directors in  
22 January '74, Dr Aronstam and Dr Rainsford both in  
23 attendance. There are some meetings for which we  
24 don't have a list of attendees, so we can't tell who  
25 was there.

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1 discussion that Treloar Haemophilia Centre was not in  
2 the same situation as the Haemophilia Reference  
3 Centres who had patients referred to them from wide  
4 areas and who provided a comprehensive service all the  
5 year around. The Treloar Haemophilia Centre was  
6 closed down during the college holidays and patients  
7 had to go to Basingstoke for treatment.  
8 Professor Bloom thought that there might be serious  
9 problems if Treloar was designated as a Reference  
10 Centre, and he wondered whether perhaps it would be  
11 better for Dr Aronstam to be invited to attend the  
12 Haemophilia Centre Reference Directors meetings  
13 without the official designation of Treloar's as  
14 a Reference Centre. Dr Jones suggested that  
15 Dr Aronstam should be co-opted to attend the  
16 Haemophilia Reference Centre Directors meeting as the  
17 Expert in Adolescent Haemophilia Management in the  
18 same way as Dr Craske was invited to attend the  
19 meeting as the expert in Hepatitis. It was agreed  
20 Treloar Haemophilia Centre could not be designated as  
21 a Reference Centre but that Dr Aronstam should be  
22 invited to attend the meeting of Reference Centre  
23 Directors on account of his special experience of  
24 managing haemophilic boys at the College."

25 And that is what then happened. So the

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1 But if we then go to January '77, Dr Rainsford  
2 and Dr Kirk were both in attendance; October '77,  
3 Aronstam, Kirk, Rainsford and Painter, so four  
4 representatives from Treloar's in attendance; in  
5 November '78 it's just Dr Aronstam; November '79 it's  
6 Dr Aronstam; and then, when we move on into the early  
7 eighties, Dr Aronstam was present, September '82,  
8 October '83, September '84, October '85. So he was  
9 a regular attender of Haemophilia Centre Director  
10 meetings. He was then a member of the AIDS group of  
11 the UKHCDO, which met from January 1985 onwards.

12 But it wasn't simply a question of attendance at  
13 the general annual meetings of Haemophilia Centre  
14 Directors. If we look at LOTH0000012\_122, this is  
15 a meeting of the Reference Centre Directors on  
16 14 September 1981 and, if we go to page 6, we can see  
17 bottom half of the page there is a heading  
18 "Designation of the Treloar Haemophilia Centre":  
19 "The question of designation of Treloar  
20 Haemophilia Centre as a Reference Centre was raised by  
21 Dr Savidge. He drew attention to the fact that the  
22 Centre had very special and wide experience in the  
23 management of haemophilia in adolescents and played an  
24 important role in introducing the boys who attended  
25 the College to home therapy. It was pointed out in

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1 Reference Centre Director meetings after 1981 were  
2 attended by Dr Aronstam. He was there at the 1 March  
3 '82 meeting; the 6 September '82 meeting; the  
4 14 February '83 meeting, that was one of the very  
5 significant meetings in terms of discussions about  
6 AIDS; the 19 September '83 meeting; the 13 February  
7 '84 meeting; the meeting on 10 September '84; and then  
8 18 February '85.

9 So he was not in attendance at the May 1983  
10 special meeting of Haemophilia Reference Centre  
11 Directors but otherwise he was effectively privy to  
12 all the information that was being discussed at  
13 Reference Centre Directors meetings, including of  
14 course the various updates provided by Dr Craske, of  
15 particular relevance when we look at knowledge of risk  
16 of HIV and AIDS.

17 In addition, as again we'll look at probably on  
18 Friday, when I look at the question of research,  
19 Dr Kirk was a member for a period of time of the  
20 Hepatitis Working Party in the seventies and so he too  
21 would have had access to some of the particular  
22 reports being produced by the Hepatitis Working Party  
23 and by Dr Craske on the issue of hepatitis.

24 So the next topic I'm going to address orally is  
25 a rather large and significant topic: knowledge of

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1 risk of hepatitis and HIV. I don't think there's much  
 2 to be gained from starting it at nearly quarter to  
 3 five in the afternoon after a long day. So I'm going  
 4 to suggest that I can pick that up tomorrow afternoon  
 5 after we've heard the evidence of the headmaster,  
 6 Mr Macpherson, in the morning.  
 7 **SIR BRIAN LANGSTAFF:** Yes. So Mr Macpherson tomorrow  
 8 morning, at ten o'clock. Ten o'clock tomorrow.  
 9 **MS RICHARDS:** Thank you, sir.  
 10 **(4.38 pm)**  
 11 **(Adjourned until 10.00 am the following day)**

<b>I N D E X</b>		
1		
2	Anonymity Order .....	1
3	WITNESS W3044 - MR BC (affirmed) .....	1
4	Questioned by MS FRASER BUTLIN .....	1
5	Questions from SIR BRIAN LANGSTAFF .....	51
6	LEE STAY (affirmed) .....	56
7	Questioned by MS RICHARDS .....	56
8	Questions from SIR BRIAN LANGSTAFF .....	112
9	Presentation by MS RICHARDS .....	119

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<p><b>MS FRASER BUTLIN:</b> [21] 1/24 15/2 16/2 16/4 16/14 16/18 16/23 17/8 17/17 23/10 24/1 24/5 24/9 24/12 24/17 28/24 29/5 29/8 29/15 29/21 53/12</p> <p><b>MS RICHARDS:</b> [41] 56/12 77/23 77/25 78/9 78/13 84/19 84/22 85/11 112/16 115/22 118/25 119/11 125/8 125/11 125/22 125/25 130/22 130/24 131/4 131/11 132/22 134/8 134/12 134/18 135/9 136/9 136/15 137/1 140/12 143/23 144/5 144/12 144/15 148/25 149/4 163/19 167/13 178/14 178/22 178/25 189/9</p> <p><b>SIR BRIAN LANGSTAFF:</b> [82] 1/4 15/1 15/23 16/3 16/13 16/16 16/21 17/6 17/16 23/1 23/21 24/3 24/6 24/14 28/4 28/13 28/19 29/4 29/6 29/9 29/16 51/6 52/7 53/11 54/4 54/7 54/12 54/15 55/19 56/2 56/8 77/21 77/24 78/8 78/12 84/15 84/21 84/23 85/8 112/22 113/1 113/5 113/17 113/21 113/23 114/7 114/22 115/5 115/21 118/12 119/4 119/10 125/6 125/9 125/19 125/24 130/16 130/23 131/3 131/5 132/21 134/4 134/10 134/13 134/25 136/6 136/11 136/21 140/8 143/17 144/2 144/7 144/13 148/21 149/3 163/13 163/18 167/12 178/8 178/20 178/23 189/7</p> <p><b>THE WITNESS:</b> [5] 24/10 24/16 29/22 115/24 118/24</p>	<p>'75 [3] 58/10 139/22 185/15 '76 [1] 59/20 '77 [5] 139/22 140/8 142/8 186/1 186/2 '77 from [1] 139/22 '78 [4] 4/6 159/20 163/6 186/5 '78 it [1] 4/6 '79 [2] 4/12 186/5 '80 [1] 6/6 '80s [1] 185/11 '81 [1] 71/23 '82 [8] 10/6 12/9 72/1 72/4 78/3 186/7 188/3 188/3 '83 [14] 16/12 51/16 72/6 72/8 72/10 75/18 76/13 77/2 77/12 78/16 79/23 186/8 188/4 188/6 '83 and [1] 51/16 '84 [18] 17/25 17/25 18/1 19/12 21/10 21/15 21/22 27/4 29/20 29/24 30/5 37/14 51/16 83/25 86/13 182/8 188/7 188/7 '84 and [1] 37/14 '84 should [1] 51/16 '84 would [1] 27/4 '84, [1] 186/8 '84, October '85 [1] 186/8 '85 [8] 28/1 30/18 37/14 82/6 82/12 83/25 186/8 188/8 'can [1] 5/15 'hepatitis [1] 129/4 'Lister' [1] 129/11 'normal [1] 171/23 'restore' [1] 171/11 'rough [1] 171/15 'T' [1] 181/7 'Tolerance [1] 10/5</p> <p>-</p> <p>-- and [1] 99/4</p> <p>...</p> <p>...frequency [1] 175/20</p> <p><b>0</b></p> <p>0.01 [1] 40/16 0000517086 [1] 144/4 002 [3] 84/18 84/18 124/12 003 [1] 123/1 004 [5] 10/25 13/17 26/14 29/4 138/7</p>	<p>005 [1] 79/19 007 [1] 181/22 008 [3] 119/18 126/18 143/23 01 [1] 27/24 014 [1] 130/7 016 [2] 6/24 177/18 018 [1] 12/17 019 [1] 9/25 020 [1] 154/21 022 [1] 70/16 023 [3] 73/21 84/18 84/20 028 [2] 75/13 84/25 029 [1] 146/17 044 [1] 180/7 051 [1] 26/21 053 [1] 67/1 054 [1] 67/23 061 [1] 20/20 068 [1] 173/22 077 [1] 129/23 083 [2] 8/2 167/16 084 [1] 163/23 086 [1] 144/4 089 [1] 81/10 090 [2] 83/4 137/13 098 [1] 120/13 09N6974 [1] 130/20</p> <p><b>1</b></p> <p>1 April 1981 [1] 169/25 1 February 1983 [1] 16/11 1 July [1] 130/21 1 March [1] 188/2 1,000 [1] 153/14 1,153,340 [1] 139/14 1,200 units [1] 65/19 1,800 [1] 171/1 1.2 [1] 139/20 1.25 [1] 119/6 1/2 [1] 74/19 10 [4] 3/13 65/2 141/13 172/3 10 July 1980 [1] 7/1 10 March '83 [1] 78/16 10 May 1979 [1] 123/7 10 November [1] 137/16 10 November 1980 [1] 168/15 10 September '84 [1] 188/7 10,000 [2] 151/11 152/23 10.00 [2] 1/2 189/11 10.3.83 [1] 80/16 100 [5] 122/7 147/18 150/23 151/16 179/12</p>	<p>100 bags [1] 121/18 100 per cent [1] 76/10 1045 [1] 139/19 106 [1] 139/9 10th [4] 11/10 77/22 77/23 77/24 11 [5] 3/10 3/11 13/2 21/2 71/24 11 January [1] 27/4 11 January '84 [1] 29/20 11 July 1984 [1] 83/6 11.1.84 [2] 26/18 27/1 11.24 [1] 55/22 11.55 [3] 55/21 55/21 55/24 11/01 [1] 27/24 11/01/84 [1] 27/25 112 [1] 140/13 12 [7] 20/21 85/18 135/21 135/22 135/23 135/23 175/4 12 February 1983 [1] 12/23 12 January [1] 83/18 12 January 1984 [1] 82/5 12 October 1980 [1] 70/20 12.03 [1] 56/1 12.1.84 [3] 82/2 82/21 83/16 122 [1] 186/14 13 [1] 72/5 13 February [1] 188/6 13 March '83 [1] 16/12 132 [1] 183/6 14 [1] 133/17 14 days [1] 3/14 14 December 1984 [1] 181/23 14 February [1] 188/4 14 May 1979 [1] 124/13 14 million [1] 170/25 14 November 1978 [1] 173/24 14 September 1981 [1] 186/16 15 [9] 72/7 100/6 121/19 127/8 132/5 141/6 164/22 165/1 182/11 15 months [1] 103/9 15 years [1] 37/5 15-20 [1] 165/7 159 [1] 157/25 15th December '82 [1] 78/3 15th March [1] 78/5 16 [2] 31/15 132/4</p>	<p>16 January 1980 [1] 177/19 17 [3] 31/16 128/23 141/13 17 and [1] 13/3 17 December 1984 [1] 24/2 17 years [1] 141/6 18 [3] 5/5 5/6 31/16 18 April 1980 [1] 163/25 18 February '85 [1] 188/8 18 March 1969 [1] 120/16 18 May [1] 13/3 18 May 1979 [1] 146/17 182 [1] 152/23 18th [1] 151/5 19 [1] 38/6 19 June '83 [1] 75/18 19 June 1983 [1] 13/20 19 March [1] 27/17 19 March 1984 [1] 180/8 19 March 1985 [3] 26/16 29/18 81/11 19 November [1] 182/22 19 November 1979 [1] 160/23 19 September '83 meeting [1] 188/6 19.11.84 [1] 182/14 19.9.84 [1] 26/25 1959 [1] 174/3 1968 [2] 184/14 184/18 1969 [4] 120/16 122/12 150/15 150/24 1970 [2] 59/19 158/6 1970-74 [1] 158/4 1970s [8] 122/24 123/3 130/9 156/13 158/3 158/19 163/4 185/11 1971 [2] 185/1 185/3 1972 [2] 122/19 185/12 1973 [8] 119/20 122/23 139/14 139/19 140/4 142/7 152/13 158/11 1974 [7] 133/20 151/23 154/13 156/23 158/7 158/23 185/20 1975 [9] 2/9 2/11 56/22 57/8 58/4 58/15 59/20 164/8 164/14 1976 [4] 59/2 152/20</p>	<p>164/15 164/21 1977 [5] 128/22 139/14 139/19 140/4 145/1 1978 [14] 59/9 126/20 126/21 128/23 133/22 137/15 144/22 154/24 155/2 156/11 160/12 173/24 177/12 179/13 1979 [7] 123/7 124/13 129/24 131/16 133/7 146/17 160/23 1980 [14] 7/1 7/17 61/4 70/13 70/20 71/9 163/25 168/4 168/9 168/15 169/6 177/19 178/9 180/6 1980s [1] 150/4 1981 [10] 8/3 8/18 10/18 63/3 70/11 169/22 169/25 172/16 186/16 188/1 1982 [5] 9/16 12/4 34/19 70/9 90/9 1983 [20] 10/2 11/10 12/16 12/19 12/23 12/25 13/20 14/15 14/18 15/25 16/7 16/11 17/15 17/17 25/23 52/23 67/23 80/6 180/4 188/9 1984 [17] 18/23 20/21 24/2 28/14 82/5 83/6 149/17 149/25 180/4 180/8 181/2 181/19 181/21 181/23 182/6 182/21 183/2 1985 [13] 26/16 26/23 27/18 29/18 31/23 32/17 38/1 38/16 81/11 81/11 82/18 119/12 186/11 1986 [3] 86/18 87/2 149/9 1987 [4] 5/3 117/10 183/7 183/10 1988 [1] 133/7 1990 [1] 53/24 1990s [1] 93/24 1992 [1] 34/20 1993 [2] 93/12 105/13 1994 [3] 85/22 94/2 95/4 1997 [2] 90/22 90/24 1998 [1] 98/5 19th June [1] 154/24 1st October 1968 [1] 184/18</p> <p><b>2</b></p> <p>2 March '84 [1] 18/1 2 or 3 days [1] 130/6</p>
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<p><b>2</b></p> <p><b>2.30 [3]</b> 119/4 119/5 119/8</p> <p><b>2.5 [1]</b> 139/13</p> <p><b>20 [11]</b> 31/12 45/23 74/16 146/22 165/7 165/23 171/12 178/11 182/9 182/16 183/8</p> <p><b>20 March 1969 [1]</b> 150/24</p> <p><b>20 minutes [2]</b> 63/20 129/12</p> <p><b>20% dose [1]</b> 65/2</p> <p><b>20,000 [1]</b> 146/2</p> <p><b>20-30 [1]</b> 175/21</p> <p><b>200 [4]</b> 20/7 39/24 65/20 132/8</p> <p><b>200,000 [1]</b> 152/17</p> <p><b>2000 [3]</b> 39/15 40/9 40/23</p> <p><b>2000s [2]</b> 25/4 105/24</p> <p><b>2001 [1]</b> 40/23</p> <p><b>2002 [1]</b> 92/9</p> <p><b>2003 [1]</b> 95/20</p> <p><b>2007 [2]</b> 96/17 96/17</p> <p><b>2008 [2]</b> 106/25 109/4</p> <p><b>2013 [1]</b> 98/12</p> <p><b>2015 [3]</b> 101/1 101/14 117/11</p> <p><b>2017 [1]</b> 102/2</p> <p><b>2019 [1]</b> 131/14</p> <p><b>2020 [1]</b> 31/22</p> <p><b>2021 [1]</b> 1/1</p> <p><b>208 transfusions [1]</b> 131/23</p> <p><b>21 March 1978 [1]</b> 144/22</p> <p><b>21 November 1978 [1]</b> 137/15</p> <p><b>22 June [1]</b> 16/1</p> <p><b>22 March [1]</b> 27/18</p> <p><b>22 March 1985 [1]</b> 26/23</p> <p><b>22nd June 1983 [1]</b> 14/18</p> <p><b>23 [2]</b> 10/25 84/18</p> <p><b>23 April 1979 [1]</b> 131/16</p> <p><b>23 November 1983 [2]</b> 10/2 67/23</p> <p><b>23/1/84 [1]</b> 19/4</p> <p><b>23rd June 2021 [1]</b> 1/1</p> <p><b>24 [2]</b> 132/3 172/16</p> <p><b>24 bags [1]</b> 121/19</p> <p><b>25 [1]</b> 94/4</p> <p><b>25 August 1978 [1]</b> 126/21</p> <p><b>25 years [1]</b> 39/12</p> <p><b>26,000 [1]</b> 154/3</p> <p><b>26/4/82 [1]</b> 18/14</p>	<p><b>260,000 [1]</b> 157/11</p> <p><b>267 [3]</b> 84/18 84/18 84/25</p> <p><b>27 October 1972 [1]</b> 185/12</p> <p><b>27.11.84 [1]</b> 182/18</p> <p><b>27.5.75 [1]</b> 130/19</p> <p><b>27th [1]</b> 11/10</p> <p><b>28 [1]</b> 16/9</p> <p><b>28 February 1983 [3]</b> 15/25 16/7 17/15</p> <p><b>28.3.84 [1]</b> 18/18</p> <p><b>28.8.76 [1]</b> 57/14</p> <p><b>28/2/83 [3]</b> 15/17 15/19 15/22</p> <p><b>288,000 [1]</b> 171/10</p> <p><b>29 [1]</b> 156/23</p> <p><b>29 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187/13 <b>WITN1202001 [1]</b> 133/14 <b>WITN1353001 [1]</b> 133/4 <b>WITN1541003 [1]</b> 57/5 <b>WITN1541004 [2]</b> 59/12 69/23 <b>WITN1541005 [2]</b> 80/3 85/17 <b>WITN1541006 [1]</b> 90/2 <b>WITN1541009 [1]</b> 72/25 <b>WITN1541010 [1]</b> 95/3 <b>WITN1592011 [1]</b> 131/12 <b>WITN5277001 [1]</b> 128/19 <b>witness [14]</b> 1/4 1/5 1/10 1/15 1/22 11/2 66/18 67/6 87/3 87/25 128/18 132/23 173/14 190/3 <b>witness W3044 [1]</b> 1/10 <b>witness' [1]</b> 26/20 <b>witness's [1]</b> 1/11	<b>witnesses [5]</b> 54/17 73/4 122/14 122/14 133/24 <b>won't [2]</b> 132/22 169/4 <b>wonder [3]</b> 7/10 9/3 16/4 <b>wondered [2]</b> 45/20 187/10 <b>wonders [2]</b> 16/3 151/13 <b>wood [1]</b> 103/18 <b>word [7]</b> 4/22 21/25 24/7 30/4 37/16 41/6 77/7 <b>wording [3]</b> 6/15 26/20 28/24 <b>words [7]</b> 25/20 33/16 47/19 82/20 97/15 113/25 143/22 <b>work [20]</b> 35/21 46/15 46/20 46/22 59/23 60/6 64/5 94/17 97/5 97/6 105/11 106/6 106/11 106/20 107/7 109/14 118/9 153/22 162/6 170/20 <b>worked [4]</b> 2/23 14/10 51/7 113/22 <b>workers [1]</b> 8/24 <b>working [8]</b> 36/19 37/6 95/19 105/16 105/18 128/22 188/20 188/22 <b>workload [1]</b> 171/22 <b>works [2]</b> 55/1 76/17 <b>world [5]</b> 2/17 28/8 42/8 44/13 44/23 <b>worry [3]</b> 8/12 41/20 133/15 <b>worrying [1]</b> 181/8 <b>worse [1]</b> 33/25 <b>worst [1]</b> 140/25 <b>worth [2]</b> 47/2 127/13 <b>worthlessness [1]</b> 46/7 <b>worthwhile [1]</b> 35/7 <b>would [164]</b> 2/20 3/13 3/14 3/15 4/8 4/12 5/1 5/1 6/3 6/6 7/6 7/10 7/13 7/21 7/24 9/3 9/6 9/9 9/13 9/21 11/3 11/14 11/17 13/11 16/5 16/8 19/17 19/22 20/11 21/16 21/17 22/22 23/19 23/23 23/25 25/23 27/3 27/4 27/11 28/2 28/14 28/19 29/12 30/17 32/10 32/15 33/25 35/8 35/16 35/17 35/23 36/2 36/5 38/20 40/9 44/7 44/21 48/19
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(77) weight... - would

<p><b>W</b></p> <p><b>would... [106]</b> 50/24 51/11 52/5 52/10 52/19 52/21 53/19 53/20 53/21 53/22 53/23 53/25 55/2 60/10 61/15 62/19 62/21 62/22 63/7 63/10 63/12 64/13 64/18 64/19 64/21 65/3 65/5 65/8 69/4 70/22 73/12 74/7 74/13 75/4 75/11 76/1 76/4 77/17 79/13 83/17 87/14 87/15 88/14 91/12 93/11 100/11 101/9 106/6 106/7 107/5 107/18 108/4 109/20 110/19 112/19 113/2 113/17 113/18 115/22 116/2 116/3 120/5 121/1 121/24 123/18 124/4 125/7 125/8 125/9 125/12 125/22 131/20 132/13 136/19 143/19 145/3 145/8 145/10 148/16 148/23 152/4 154/2 154/17 155/13 155/14 156/5 157/10 157/19 159/14 161/16 162/24 162/25 163/12 165/8 167/7 169/8 169/9 169/12 170/22 171/9 171/11 174/10 178/12 179/21 187/10 188/21</p> <p><b>wouldn't [8]</b> 8/16 29/17 30/25 65/22 92/22 101/12 101/17 108/10</p> <p><b>wow [1]</b> 31/3</p> <p><b>write [1]</b> 46/24</p> <p><b>writing [6]</b> 14/19 71/11 151/3 160/22 162/25 167/10</p> <p><b>written [8]</b> 20/25 77/8 138/24 146/7 163/24 173/15 179/23 182/7</p> <p><b>wrong [4]</b> 109/6 111/9 111/14 148/16</p> <p><b>wrote [4]</b> 123/7 131/19 167/17 168/8</p>	<p>62/16 63/6 63/14 63/25 64/4 64/7 64/7 64/17 66/22 67/18 69/9 69/17 70/10 70/15 70/22 70/22 71/2 71/5 71/8 72/9 72/14 72/14 73/9 73/17 74/5 74/11 76/22 78/12 81/9 81/15 81/17 82/10 82/23 83/21 88/2 88/5 90/1 91/3 91/14 92/10 92/14 93/7 93/13 93/23 93/25 94/3 94/6 94/13 94/23 94/25 95/1 95/21 96/1 96/7 96/14 96/18 97/18 97/22 98/4 98/6 98/15 98/22 98/25 99/2 99/23 100/1 100/8 100/24 101/2 101/22 101/22 102/1 102/3 102/25 104/20 104/24 105/14 105/19 105/23 106/10 106/15 107/1 107/7 108/5 108/9 108/14 108/15 109/3 109/8 109/10 109/11 109/12 109/16 109/18 109/23 110/22 111/22 112/25 114/6 115/4 115/24</p> <p><b>year [30]</b> 3/17 3/18 5/9 6/6 42/6 42/8 42/10 76/1 83/5 88/21 100/2 100/2 103/7 123/12 123/18 127/10 133/11 145/1 145/16 151/6 151/11 152/24 153/14 158/15 160/19 161/7 174/10 175/4 178/10 187/5</p> <p><b>years [30]</b> 5/17 32/1 32/18 34/25 36/11 37/5 39/12 40/15 41/22 55/4 57/8 57/19 60/9 62/1 62/5 87/16 87/17 89/23 93/2 103/5 117/21 136/17 139/11 139/22 140/2 140/16 141/6 150/8 151/23 157/6</p> <p><b>years' [1]</b> 32/14</p> <p><b>yes [107]</b> 2/1 2/4 2/7 2/10 2/13 3/8 4/15 5/2 5/4 5/6 5/6 5/9 5/23 6/12 6/12 7/12 8/4 8/11 8/20 9/17 9/19 10/17 11/7 11/16 11/25 12/3 12/3 13/9 13/9 13/9 13/15 15/15 16/13 17/6 17/16 19/2</p>	<p>20/24 21/11 21/14 22/14 22/16 23/10 24/18 24/20 24/24 26/5 26/7 26/9 26/11 28/12 28/18 34/5 34/15 36/12 36/15 40/25 42/15 42/25 43/24 44/2 44/4 44/13 44/21 45/10 45/12 45/16 46/17 46/19 47/11 54/11 57/4 59/3 66/3 66/20 67/14 68/16 70/4 71/18 78/8 79/10 84/1 91/18 112/22 119/4 119/10 125/23 125/24 130/14 130/24 130/24 131/4 131/11 132/21 134/12 134/25 135/9 136/9 136/15 137/1 140/8 140/12 143/23 144/12 144/15 163/13 163/18 189/7</p> <p><b>yesterday [4]</b> 40/15 134/3 137/4 138/6</p> <p><b>yet [4]</b> 112/8 130/16 147/10 160/20</p> <p><b>York [1]</b> 127/1</p> <p><b>you [717]</b></p> <p><b>you'd [19]</b> 32/4 45/9 56/5 62/14 64/8 64/15 64/16 64/20 65/2 65/4 65/5 82/14 82/18 88/6 95/19 98/5 111/25 136/7 136/12</p> <p><b>you'll [4]</b> 123/11 137/5 150/24 168/16</p> <p><b>you're [33]</b> 8/12 20/8 24/15 26/1 30/21 31/19 36/16 36/17 36/19 37/5 37/5 37/24 38/8 44/12 50/6 54/19 56/5 57/8 58/3 58/9 59/21 60/25 66/7 69/20 70/11 70/13 70/25 71/7 72/8 80/16 82/13 91/1 109/17</p> <p><b>you've [40]</b> 5/7 8/1 22/17 33/2 34/1 34/2 34/3 36/23 37/7 46/15 51/6 52/12 54/8 54/20 54/22 57/7 57/19 72/1 74/8 82/21 91/8 91/21 92/6 92/8 94/21 95/9 96/25 98/1 98/2 98/16 99/1 104/2 104/16 105/20 107/25 110/4 114/1 118/13 118/19 118/20</p> <p><b>young [2]</b> 31/14 180/11</p> <p><b>your [198]</b></p>	<p><b>yours [2]</b> 111/17 120/7</p> <p><b>yourself [10]</b> 36/19 51/6 85/5 104/17 104/18 115/2 115/18 118/17 118/19 161/23</p> <p><b>yourselves [1]</b> 120/1</p>	<p><b>Z</b></p> <p><b>Zeitlin [5]</b> 121/12 121/16 121/22 150/21 151/1</p> <p><b>zero [1]</b> 99/14</p> <p><b>zeros [1]</b> 84/18</p> <p><b>zip [1]</b> 23/4</p> <p><b>zombies [1]</b> 46/10</p> <p><b>zoom [4]</b> 10/15 57/11 85/23 170/9</p>	
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