Monday, 8 June 2021

(10.00 am)

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

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

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

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

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

THE WITNESS: Robert Magnus Lee James.

ROBERT MAGNUS LEE JAMES, affirmed

Questions from MS FRASER BUTLIN

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

A. Yes.

Q. You have severe haemophilia A.

A. That's right.

Q. And initially, you were treated with cryoprecipitate?

A. That's correct, yes.

Q. That included home treatment with cryoprecipitate?

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

Q. How manageable was cryoprecipitate as home treatment?

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

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

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

A. Okay, I hope that helps.

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

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

A. Yes.

Q. And by then you were receiving factor concentrates?

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

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

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

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

seventies, during your teenage years?

A. *(Nodded)*

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

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

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

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

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

A. Yes.

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

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

Q. And then when you were 18, in April 1985, you were told that you had HTLV-III antibodies?

A. That's correct.

Q. Can you tell us how you came to be told?

A. I had got a bleed or a problem, there was some reason I needed to go into the hospital, and I rang up, I think, and said, "Can I come in tomorrow?" or "Can I come in in a couple of days?" Something like that. And by chance I went in with my father; because I was 18, so sometimes I went on my own, sometimes I went with him because if he was driving in then I'd get a lift with him and, while I was there, after we'd done whatever it was about whatever problem I'd got, the doctor said that they'd done this test and I'd got HTLV-III.

Q. Before you were told that, were you aware they were testing?

A. No.

Q. After you were told, what did you then do?

A. Well, when I was told, the -- well, the doctor, Dr Thompson, said it was very uncertain, I might be immune to it, I might have antibodies, I might have it as being ill, it might mean nothing at all. Then I rang up, I think it was THT the next day or the next couple of days and said, "What does this mean?" And they said, "It means you've got the virus that causes AIDS."

Q. You've described that subsequently your father had said to you that the doctor had thought very hard about telling you?

A. Yes, he told me, I think it was once when we were on holiday, that he had spoken to the doctor later and she'd said she'd spent -- she'd been up all night worrying about how to tell me, and that at -- I think at the time I was the only patient at the centre who'd got HIV.

Q. And the information she provided to you was -- it was very uncertain?

A. *(Nodded)*

Q. The Terrence Higgins Trust phone call indicated that it was HIV?

A. Yes, that -- they certainly said to me the idea of immunity was not really sensible. Then they were obviously cautious about saying the doctor is completely wrong, because people were then, but it was a very different slant on -- yeah, on the way it was described. It was -- it was much more negative than what she had said.

Q. And when you told the person on the end of the phone at THT that you had HTLV-III antibodies, you've described a particular reaction that you know many people had?

A. A number of friends of mine who were diagnosed very early with haemophilia -- or not -- or not many with haemophilia but lots without haemophilia came in. If you rang up then, they'd be really surprised. It was "the gulp", I discovered it was called and it's because, at that time, there were so few people diagnosed with HIV, it was a few thousand, even though it was the Terrence Higgins Trust and they were a helpline, they didn't often actually get that many positive people ringing up saying "I've got HIV" or "I've got HTLV-III, what does it mean?" So it was, yes, quite a surprised reaction. And I wonder also if there was some surprise about what I'd been told.

Q. And you've described that "the gulp" was something that several people experienced --

A. Yes.

Q. -- when they told people about their diagnosis.

A. Yes. Yeah, because it was so unusual at the time.

Q. You went on to university.

A. Yes.

Q. What difficulties did you initially face there because of your diagnosis?

A. When -- at the time, because we didn't have anything like an Equality Act or Discrimination Act, the way it worked at university, if you were going to university and you had any kind of disability you had to write about a year, 18 months in advance to the university and say, "Can I come to your university? Can you cope with my disability?" And they'd write back and say yes or no. And I wrote to a number, and Swansea, which is where I went, wrote back to me and said, "Fine, it's not a problem". And on my open day I went up there, it was a beautiful sunny day, there was the beach, and I visited the medical centre on campus, and that was all fine about me having haemophilia. And then, when I arrived to start my degree, I went into the department and before I had signed up to join the course I was doing, the head of department came over to me and said, "Can you not do this? Can you not sign up here? We'd like you to go and see someone", the next day. And it was someone in administration in the university.

And so the next day I went to the administration building and the person I was meant to see wasn't there. And I sort of moved around different people, not quite sure what I was doing and nobody quite sure what to do with me, and I ended up seeing the head of undergraduate admissions, that I was a bit intimidated by because that seemed like a really powerful position, and he had no idea if it was going on. And then he said, "Go away for half an hour, come back, and I'll find out what's going on."

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

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

Q. You also have hepatitis C.

A. Yes.

Q. How did you find out about that diagnosis?

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

A. Yes.

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

A. Yes.

Q. Can you tell us about that?

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

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

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

A. *(Nodded)*

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

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

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

A. My first job was full time. But since then, I've really only ever been able to work part time. I did have one other full-time job and I'd better not say what it is, but there was so little to do I actually only did it part time and pretended I was full time. But yes. And often that was fitting in things like treatments, interferon, problems with bleeds, I've had number of operations, joints being fused, lots of elbow operations. And the last, yeah, at least 10 years I'm just too tired. I can't work full time and do the other things I want to do in life. So I work part time, and have done, yeah.

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

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

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

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

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

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

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

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

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

A. Mm.

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

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

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

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

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

Q. Following on from that, in relation to how it affected treatment and care going forwards, you've mentioned that there weren't necessarily referrals to immunologists or GU clinics. From your own experience and perhaps from the experience of those you've campaigned with, what effect did that have on the treatment that was provided?

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

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

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

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

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

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

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

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

A. Yes.

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

A. Yes.

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

what you mean by that?

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

Also, was it, I think Professor Tuddenham said it breaks the first rule of epidemiology. Just because you've got two so far, doesn't mean you'll get none later and, therefore, it was a ludicrous statistic. And at the time there were papers published amongst -- about to be cohorts of haemophilia there was one I think in Newcastle and these were all at the start of 1983, which found that we had a reversal of the C4/CD8 ratio amongst our groups and exactly the same finding was being seen amongst gay men who were on the scene and having a lot of sex and likely to have HIV, and was also seen amongst drug users and that had been published at the end of '82, and then, yeah, there's the article in the New England Journal of Medicine, Desforges, which talked about this.

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

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

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

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

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

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

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

fears.

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

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

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

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

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

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

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

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

A. Yes.

Q. First of all, in terms of the treatment approach. You have said that clinicians didn't necessarily refer on.

A. Yes.

Q. How much do you think that the stigma attached to hepatitis C influenced the treatment pathways that were followed?

A. I think it influenced it a lot. I mean, certainly amongst liver clinics, they were often very reticent to treat me, certainly current drug users, which then makes it odd that they would have been much happier to treat people with haemophilia. But I think it was that mixture of also not wanting liver doctors perhaps to know that they'd got this disease as a treatment from the haemophilia doctor. And that -- I'm sure also there were people with haemophilia who are struggling with this diagnosis, and they don't want it then to be associated. Some of the stories we heard at the beginning about people's treatment by just, like, neighbours and stuff was horrible.

I think that stigma, and certainly when you're diagnosed with a condition, you start to learn more about it, you will pick up, if you've got hep C, "Oh, it's predominantly a disease of drug users", or it

seems to be. It certainly was at that time. So if you're also not comfortable with that and your perception is going to be, "Well, if I go to the clinic that's all I'm going to see and I don't want to be sitting in a room with those people", then you're not going to be pushing your doctor for a specialist referral. And if your doctor is happy to continue on, bumble away in an area that's not their speciality, that's what's going to happen.

Q. So from your perception, how much of it was the doctors being protective towards patients who were uncertain, and how much of it was the doctors being influenced by the stigma around the disease? Was it six of one and half a dozen of the other?

A. Probably. They're sort of tied up because if the doctor is prejudiced or thinks that drug users, "That's a terrible thing, you don't want to be associating with them", then they're acting on that stigma, but if they're also -- if that's also a part of being protective, and there's also that -- yeah, just general protection of looking after their patients. And if we had a very patriarchal 'Doctor knows best' situation, and that they -- a lot of people would just do what their doctor told them, but, yeah, I suppose kind of half a dozen of one and six of

the other because they were also a bit mixed, the stigma and the protection.

Q. And through your contacts in your campaigning and the organisations you've been involved with, what impact did that treatment approach have on the relationships between clinicians and patients?

A. I think in the long term, it -- it ruined it. It's the -- if -- for someone like myself, if you went through the period of lots of repeated messages that it's always better to take your factor, the risk of the -- of AIDS is far -- you know, the risk of not taking your treatment is far outweighed, I'd keep taking it. And then so many of us were diagnosed. And then you have the situation of hepatitis C.

So even for those who didn't get HIV, who must have spent a couple of years wondering and hoping that the -- and by the time they get to be more confident they have not got it, we then go through that period with non-A, non-B, and we get diagnosed with hepatitis C, and the initial response is, "It's fine, it's a mild disease, you don't have to worry", and it's not. And when it becomes clear it's not, all of us -- and there might have been a very small number of very young children who would have been born after the HIV thing, before hep C, but everyone lived through

that or everyone's parent lived through that, it's really hard to trust a doctor, when they got it wrong so badly twice, to have minimised the severity of one and got it wrong, even when they knew that there was a proportion of people with -- had cirrhosis, and there were -- minimising that and saying, "Oh, well, it's only a small number" -- it seemed quiet a large number to me -- and then it progresses and gets worse, is -- and, yeah, one in a thousand and then over a thousand people get HIV, it -- it's really hard to trust someone when you think: well, what is your knowledge?

And so, yeah, for me that was: well, I need to find this out for myself. I need to be the person who knows about it. And certainly I always knew more about HIV treatment than any of the haemophilia doctors I saw. I knew more about which combinations worked, which didn't, which you couldn't have together, that type of thing. And I just -- I ignored them if they ever wanted to speak about anything other than haemophilia because I didn't think they had the knowledge.

Q. You've worked with both haemophilia focused organisations and broader AIDS organisations over the years.

A. Mm.

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

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

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

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

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

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

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

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

A. Mm.

Q. Did you see a similar difference in the campaigning

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

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

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

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

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

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

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

Q. You talked about how you came to seek to have as much knowledge as possible so you could influence your care. Has your campaign work impacted on the care you have received in any other way?

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

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

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

A. Yes.

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

us about that group?

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

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

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

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

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

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

A. Mm, yeah.

Q. What was your involvement with them thereafter?

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

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

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

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

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

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

organisations. In some ways I felt I was the only one who was -- being done for that because I was the only one prepared to.

Q. In terms of your media work, again, what were the aims of doing that?

A. That was part of the campaign for compensation. And having been given this through our medical treatment to then just be ignored by Government and then pretend that, well, that's just what happens. Then there was the initial -- I can't remember whether -- I think I started before the initial announcement of the Macfarlane Trust money, to make it public, that this was a -- a wrong that was done, certainly. Under that Government and the previous governments, they had failed to protect the health of over 1,000 people, and we expand later on for hep C., and that at they needed to be held to account for that. And because I could do public work, I could put my face to it and I always felt it was better if you could have a face to a stigmatised condition, if you're silhouette, it can almost make it repeat and highlight that. I could do that, and I wanted to do that. I was happy to appear in -- it was part of one of the newspapers, I can't remember if it was The Times or The Sunday Times, did it as a sort of campaign, so I was one of the people

that took part in that, and just talked about what had happened in my life and what it meant to be a young man who was going to die.

Q. We've got an example of one of those articles, if I can put that up. Soumik, it's HOSC0022166, please. If we can go to the first column. It's an article from the Sunday Times, 15 October 1989, where you've talked about your own situation, and also dealt with the -- some of the legal process. If we can go to the bottom of the second column, Soumik.

I'm sorry, it's the bottom of the first column.

It talks about you having been involved in the legal action, and saying:

"How can people be put in my situation? I can't tell you how used and worthless I feel sometimes."

A. Mm.

Q. "Money would not compensate me for the loss ..."

Sorry, could we have the top of the ...

"... at least it would give me the security to make the best of the life I have."

So it tells your story but also talks about the need for action.

A. Mm, yes. And that worthlessness and loss, that mixture of the stigma around you've got this horrible disease, but also that -- a health system that doesn't

care and a Government that doesn't care that people are going to die, that's what happens, and, yeah, the legal process, and I started -- I was fortunate being a student when I started my legal action, which meant I got legal aid, so I could start suing the -- I wanted to sue everybody. It was like you had to sue your doctor, your health authority, your hospital, Department of Health, the Secretary of State for Health, everybody.

My doctor was at least very good about it. She just said, yes, you should. She didn't take it at all personally. And it became fairly clear to me actually very quickly that the legal campaign was never going to win, but that didn't matter. It wasn't about that. It was keeping it in the newspapers, it was putting pressure on MPs, it was also highlighting how the continuous back and forth of "Will you make these documents available", "No, in the national interest they shouldn't be available", and you'd have minutes of blood transfusion committee meetings being kept secret for the national interest. Are they really that exciting? And that was a way to do it. And also there was a point where I realised, if we lose in court, that looks so awful for a government: we dragged everybody through this, probably half of them have died, and we're still refusing to do anything about it.

Q. Just staying with the media work you were doing, was there any impact on you personally because of that media work? Did anything follow from that?

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

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

It wasn't huge. There were bits, and certainly some of the things -- I've also had some really positive things. I can remember doing something and it would probably be 10 maybe 15 years ago, just in my local paper in Brighton and going into the butchers and he'd read it, and he was just, "Wow, that's awful, what a terrible thing to happen to you". And I can remember going to football one day and one of the guys I sat next to, who I probably might have said I had haemophilia but I might not have, and he just -- we were on the bus and he sat down and he said he'd read the article and sort of, "God, yeah, you should campaign, what can I do to help?"

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

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

A. Yes.

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

A. Okay, yeah.

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

A. Yeah, well, it started off in Cardiff, and there was a social worker there, Mary Dykes, and she got together a group of people, and sort of pushed them a bit, and they decided, these four guys, that they'd start a group. And I think they first had a meeting in a hospital and that didn't feel at all right, and then one of them new a landlord of a pub so they all met in the Birchgrove pub, which is in the Birchgrove area of Cardiff, and that's why it's called Birchgrove, and it started off, everybody would just go to the pub and it was the guys with haemophilia, their wives, parents, children, anyone kind of associated with it. And it was just to meet and talk.

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

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

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

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

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

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

A. I mean, some of the magazines are very much about sort of feelings or, I don't know, support type things. So it was quite easy amongst our group to get that type of thing. In terms of the medical information, I can remember the chair, he would go to Cardiff University Library and he would read medical journals, so he was finding stuff, or we'd take stuff from some of the HIV treatment organisations, and a lot of them would happily let you reprint, republish. So we'd do that.

In terms of things -- if it was about social care or things you might be able to get, or housing issues, it would often be speaking with social workers or people who knew that system. Those would probably be the main, those would be the main sources.

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

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

(11.11 am)

(A short break)

(12.40 am)

SIR BRIAN LANGSTAFF: Yes.

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

A. Yes.

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

A. Yes, that's right.

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

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

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

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

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

The one I particularly remember, and we wrote about it in Birchgrove magazine, was the issue of sperm washing, that it wasn't available, then it was available, then it wasn't available, then, like, it was available, and it was just -- that seemed to typify this back and forth of the group that was making those decisions.

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

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

A. Yes.

Q. -- and sometimes the Macfarlane Trust.

A. Sometimes we'd convince them to pay for it, yes. [Laughs]

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

A. They came out of frustrations, always, that -- I think the first one that the Macfarlane Trust did itself was a customer -- it was a customer service -- and that was because we were saying, "You're not doing what you're meant to do to, you're taking too long, your administrative processes are poor, you're inconsistent". And they employed a company and they produced a report, and the report just said they were really good because they answered the phone quickly or they answered -- they turned round letters very quickly. And it wasn't -- as I mentioned in my statement, my friend who was chair of Birchgrove at the time, it doesn't matter how long it takes them to answer the phone, it's what they say when they answer it that mattered. And that was what we were trying to get at.

So after that --

Q. Can we just stay with that survey report?

A. Yes.

Q. It's the Public Attitude Survey report?

A. Yes.

Q. The PAS report?

A. Yes, PAS.

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

A. Yes.

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

A. What should have been addressed was, first of all, being -- it sounds awful, but being nice to people on the phone, being sympathetic, being understanding when people were angry, because that shouldn't be surprising. And upset. That -- having a system that allowed them to make a decision quickly. And also being able to provide things that were needed and, as our needs changed, coping with that quickly. And I know to some extent that's difficult, but that's -- that was their job.

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

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

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

A. Mm.

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

A. That came out of a conference, a Birchgrove conference, and just talking about the difficulties of the Macfarlane Trust, and why they were so difficult, and why they were not meeting needs and they were -- why they had decided that their sole purpose was to give out little bits of money in a sort of slow process.

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

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

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

A. Yes.

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

A. Yes.

Q. -- in 1998.

A. Mm.

Q. Those last two, what were their themes?

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

And the Voice of the Registrants I think came out because there was a need -- there was always a need for a needs assessment. Before the Macfarlane Trust were prepared to do things, they would always talk about, "Well, we need to do a needs assessment". So we'd do one and then it would be out of date by the time we'd got round to doing something, so they'd do another needs assessment. And that was one of the ways we thought that if we can get, yes, the voice of the registrants, what people feel they need and what is important to them, then it becomes a much longer lasting document. We can go back to it a few years later, and say: if we look at that, you can see here some of the things that are needed.

Q. So Birchgrove are producing these reports over the years, providing them to the Macfarlane Trust?

A. *(Nodded)*

Q. And what was the response you got in relation to them?

A. The response was generally -- it's kind of a Civil Service response, I suppose. It was, "Oh, yes, yes, we need to do better, and we can look at these things". And I mean there would be small things that would change, but the fundamental ability of the organisation to do what it was meant to do never changed. And the idea of it moving into other areas just took so long.

We did -- they did, after a long time, start to provide finances to run residential weekends so people could get together, and so Birchgrove stopped having to raise money for that, which was, of course, a great help.

And then, when one -- they'd had the first couple and it was suddenly, "Oh, this is such a great idea", and that felt -- that felt so frustrating. We've been telling you for ages to do this and you finally get to do it, and you think: ooh, isn't it really good?

And they ran for, yeah, quite a long time. And they had a big impact on people, as the Birchgrove conferences had, bringing people together, and families.

Q. The Partnership Group then came into existence. What was your involvement in that?

A. I discovered a letter, actually, I'd had -- that I wrote to Peter Stevens about the Partnership Group quite early on, where I said, "What is the point of this group? What is it trying to do?" And it reminded me that it formed actually out of a previous committee which was organising events, and that was to organise some of the initial weekends. There was a few from The Haemophilia Society, a few people from Birchgrove and a few from the Macfarlane Trust, and it was a very -- it was a task group. You did the event. And then, yeah, they decided to introduce a -- the Partnership Group, and they really just migrated everybody over from that to this.

And it was meant to be a form of communication between the registrants who were interested in going forward and the Trust itself. It was actually the second attempt they'd had to do that. When it first formed, they -- they wrote to people and asked if they could have -- I think it was a letter group for

consultation. But as far as I can tell it never consulted.

I wrote back and said I'd happily join, and I got a letter saying I'd joined, and then I don't think I was ever consulted on anything.

So the Partnership Group, we did at least get the chance to discuss things, and some quite strategic higher level, such as: the approach you're taking of dribbling the money out very slowly will not work with Government. You need to run it down to nothing and embarrass them, and only when they're embarrassed are they going to stump up more cash.

And that was a big source of tension on the two sides between some of us and the way that those running the trust were -- they'd -- yeah, not prepared to support campaigning. That also seemed annoying. If you won't do it publicly, will you provide support facilities for it?

Q. One of the things you were particularly -- you particularly sought to achieve was having registrants on the trust board?

A. Yes.

Q. And you sought to become a trustee?

A. Yes, yes, I offered myself to be a trustee at a meeting very early on, and it was when -- it became

apparent, and I think it was announced at the meeting, and it was probably the registrants at the meeting asking: are any of the trustees paid for the role they do? And it came out that: no, but it is possible to be a paid trustee, and you can't be a trustee, as registrants, because you get money out of us. It's just not possible.

So I said: well, how about we convert the amount of money you give me -- because I was getting my I think it was £15 a week regular payment -- let's convert that to a wage, pay me as a trustee, and I won't apply for any single grants.

And the Reverend Alan Tanner then -- well, he didn't really say no, he just said, "Well, what skills have you got? How can you be a trustee?" And, rather sweetly, my father pointed out I had a couple of degrees, I was a qualified social worker, and I was chair of a number of voluntary organisations.

But that -- that would seem to typify that resistance. And yes, so ever after that we were pushing -- or I was pushing. I have a particular belief in patient involvement. If someone is making decisions about me and my life, I want to be involved in that decision. I don't want to be taken over my head.

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

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

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

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

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

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

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

A. *(Nodded)*

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

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

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

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

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

Q. That was your kind of suggestions to them?

A. Yes.

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

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

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

Q. So you made the suggestions of how you thought that particularly the categorisation should be done. What response did you get to that?

A. I didn't get any individual response, I don't think. I assume the Government produced a document which highlighted what had been said in a consultation. That's a fairly standard practice. But -- and then they, yeah, they set it up the way it was, with the rules as they were.

Q. Robert, I want to move on to your involvement and patient involvement in the development of treatments, your role as a treatment activist. Firstly in relation to HIV, can we start with the UK Community Advisory Board?

A. Okay, yes. The UKCAB is a group that I was part of the setting up of, and part of making it a bit more independent from the original organisation it was very closely linked with. It brings together treatment activists in the HIV sector, so it's predominantly people with HIV. It has about 300 members, with an online forum, and the specific reason for bringing it together was because pharmaceutical companies would often claim to have done consultation with the community, which was -- in HIV, they'd invite the half

a dozen people with HIV they knew, and talk to them, and then it would come out.

A friend of mine, Simon Collins, he felt that was completely wrong, we needed something independent. If you're going to consult, actually consult. And so he got together a group of people that he thought would be good, which included myself, very nicely, and we would then invite those pharmaceutical companies who were presenting their trials or planning a trial, to come and expose themselves to us, and talk about it.

We did initially try charging them for it but they were so bad at paying and so slow that we gave up trying to get them to contribute money. It just wasn't worth it. It cost more staff time or work time or volunteer time than it did for the few hundred pounds to pay for the room and people's travel expenses.

We would then question them on that, and we would push them to make those -- to trial those drugs in the right sort of people. So in HIV, if you have people who are resistant to some drugs and there's a new drug in that category, you want to know if it's going to work in that group or not. From the pharmaceutical company perspective, they want to make

a profit so they don't want to trial it -- they want to trial it in the people it's most likely to work in. So it was often around that. The other issue particularly at the start was side effects: tell us what the side effects are, and in detail what those side effects are.

Certainly at the very beginning there was this phrase that they would say about any drug "generally well tolerated", and all that really meant was that nobody died during the treatment. You had no sense of what that was.

So it was getting -- and now you can see in most trial papers when they're published, it will list the side effects, they're specifically mentioned and graded in terms of severity. So a lot of it was around that, and then also interactions with other medications. So if you're going to produce a treatment, people take other medications. If it's going to be available to women, some of them take the contraceptive pill. You need to know if it works together, if there's a problem. If they've got liver disease and they're taking interferon, if it works with that. A variety of those medicines, and those have become more standard, not just through UKCAB, but there's also a European group and some US groups that

have been lobbying that.

Q. You've also been very involved in relation to hepatitis C treatment --

A. Yes.

Q. -- and you've been involved in two international groups, firstly H-CAB, can you tell us who they are?

A. Yeah, H-CAB was set up by a woman, a friend of mine, Tracy Swan, who worked in New York, the Treatment Action Group, I think they're called, and it was just when the DAAs were appearing for the first time, and we knew that -- well, they looked very promising, and we desperately wanted to make sure that they trialled -- their trials included the people who had cirrhosis, and who had HIV, and that they wouldn't be excluded from the trials in the way they had been excluded from the first trials within interferon, pegylated interferon, ribavirin. And also to try to -- particularly get drug companies, when they were setting up trials, to set up trials to include those groups but also to include more women in the trials, more black people, to make them more similar to the group of people who were actually going to be treated with the drug.

And, I mean, it's an interesting experience because once you start to learn this stuff and you read all these papers repeatedly, when you meet some of the pharma companies, they know less than you. And that's quite a valuable source of influence. But also, certainly for me, that was very surprising, that I know the results of another trial that you don't. That's only because I read it, you know, you could have read it in a journal.

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

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

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

A. Yes.

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

A. Yes.

Q. Can you tell us about the EATG?

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

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

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

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

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

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

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

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

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

A. Yes.

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

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

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

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

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

A. Yes. Initially --

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

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

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

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

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

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

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

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

A. Mm.

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

A. Yes.

Q. -- et cetera?

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

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

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

different genotypes?

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

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

A. Mm.

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

Could we have WITN1004007, please.

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

"The introduction of the oral treatments for hepatitis C is a major change in the management of this disease and NHS England is supporting the implementation of these treatments in a stepwise fashion with our previous early access scheme for decompensated cirrhosis, the second access scheme for all patients with cirrhosis soon to be available, and the formation of the work programme to establish access to oral drugs for patients with F3 liver fibrosis in conjunction with an effective program of surveillance for other patients and a focus on the specific needs of the complex patient groups with hepatitis C."

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

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

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

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

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

To which the answer is:

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

Then over the page, there is the question:

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

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

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

Raising points about the costs of treatment.

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

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

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

This is obviously their response that was produced for NICE.

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

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

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

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

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

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

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

Yeah, that annoyed me, that response.

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

A. Yes.

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

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

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

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

A. Yes.

Q. -- response --

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

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

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

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

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

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

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

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

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

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

Why was that view taken and presented?

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

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

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

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

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

A. Yes.

Q. As well as the BASHH general secretary.

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

A. Yeah, yes. And also just -- ten points, four pages. There was a lot we weren't -- yes, there were the whole committee. And there were other supportive letters that said similar things from some of the other clinical groups. The Royal College of Physicians I think lobbied about how delayed this health technology appraisal was -- had been, the British Society of Gastroenterology, the British Viral Hepatitis Group. A number of other bodies were lobbying with very similar sorts of points.

Q. And what was the outcome of this?

A. It was approved. It was -- passed its health technology appraisal. And then NHS England introduced rationing, which was not meant to be the way it was -- happened, but for reasons I am not -- I don't quite understand, it was allowed that this was to be rationed. And so it was rationed in the way that there were -- only specific hospitals could prescribe the drugs. They all had to be in an ODN. And I heard from one doctor in London that they all had to meet on a Sunday because they wouldn't authorise an ODN unless every single clinician who was going to be involved in the prescribing was sat in the same room at the same point to set this up.

And they would then -- each hospital would be

given number of patients per month they were allowed to prescribe this for. They were not allowed to prescribe for any more. If they prescribed any less, it would then be cut. In the way Government budgets work, if you don't spend it all, they immediately reduce you the following year. And -- yeah, it -- it was just a very -- it was in a way of doing rationing.

And they also managed to get it delayed I think an extra -- I can't remember because -- it was an extra period of time before it was even available on the NHS. So -- and sort of continuously pushing it back before people could get access to these medications.

Q. You've indicated in your statement and referred to the judicial review by the Hepatitis C Trust on the rationing system which was refused in 2016?

A. Yes, they took -- judicial review on the grounds: this is rationing and we don't have rationing when a drug is approved by NICE, but it seems we do.

Q. Did the Hepatitis Committee do anything further in relation to that, or was that really there at the end of their involvement?

A. The end of our involvement in terms of the NICE and approval, but then we would still produce -- well, in some ways we stopped producing guidelines. We'd

produce lists of best thing you can get in England rather than guidelines of what would be the best drug to prescribe. It was much easier in Scotland, because the Scottish -- it's the SCM, I think the Scottish Committee on Medicines, if I've got the name right -- they had approved far more DAAs. So in Scotland they could prescribe the best combination whereas in England it was whatever NHS England is paying for.

Q. I want to move on to my final area with you, and that is that you were particularly involved in the Living Histories Project that was established. Can you tell us how that came to be set up?

A. That came to be set up -- I'd met Sian Edwards -- who has sat on one of the expert panels on the Inquiry -- when I'd moved to -- near London and become a patient at St Thomas'. And she would run -- it was a nursing course and they wanted to appoint -- where someone with HIV would come and talk about living with HIV. So I went and did that and I became friends with her. And then, later, she came back and actually got a job as a nurse in the Haemophilia Centre. And just chatting with her over the time, we both felt what had happened to people with haemophilia and HIV was so dramatic, and a piece of history that shouldn't be lost, and we both wanted some way of capturing it.

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

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

So not just the HIV bit but the haemophilia bit, the hepatitis C bit, treatment, early life, childhood, and we collected that, and the British Library wanted to store it, so we stored it there, and once we'd finished, we then realised, it became a very obvious, there's a whole group of people we'd missed here and that's the ones who have died, and it's the families, the relatives of these people. So we got another round of funding, and we interviewed, oh, parents, children, nephews, uncles, um, mothers, brothers, sisters, as many people who were close to someone, and they weren't all someone who had died, but in a lot -- for the majority of them it was where someone had died.

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

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

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

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

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

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

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

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

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

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

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

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

Q. Just pausing there and thinking more broadly --

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

MS FRASER BUTLIN: I'm so sorry.

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

MS FRASER BUTLIN: I think I'm back to normal, sir. Sorry, my voice just caught in some water.

Thinking about those projects to capture the history and the lived experience of people who have been through this situation, what is your view of whether your lived experience and those of others has been valued by the medical community or the establishment?

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

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

or hep C, people who have died.

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

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

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

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

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

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

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

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

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

MS FRASER BUTLIN: Thank you, sir.

SIR BRIAN LANGSTAFF: So two o'clock.

(12.45 pm)

(Luncheon adjournment)

(2.00 pm)

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

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

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

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

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

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

A. Yes.

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

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

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

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

SIR BRIAN LANGSTAFF: Not on the transcript.

MS FRASER BUTLIN: Thank you.

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

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

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

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

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

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

A. *(Nodded)*

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

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

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

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

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

A. There was discussion about the idea of interferon resistance. No one had ever actually demonstrated it ever existed. There were obviously people for whom it just didn't work, but whether that was because the virus was just some how resistant to interferon or it was just your immune system couldn't build up and get rid of it, it was -- it was never confident. And there was almost the opposite point of view, which was that the -- well, if you're taking it and you get what's called a breakthrough, so you can now detect hepatitis C in the person, then you stop. Obviously it's not working, you stop. And that would be the situation where you'd be thinking maybe someone is resistant.

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

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

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

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

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

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

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

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

SIR BRIAN LANGSTAFF: Yes, I do.

Questions from SIR BRIAN LANGSTAFF

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

or even avoiding stigma in future?

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

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

SIR BRIAN LANGSTAFF: Thank you for that.

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

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

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

A. Yes.

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

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

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

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

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

So my experience was that it got better if you

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Cady, Paul, Gary, John, Martin, Myrian, Cathy, Julia, Prath and David. Thank you.

SIR BRIAN LANGSTAFF: You said towards the end of the evidence this morning that an advocate asked about the project which you conducted with Sian Edwards. You said, I think with a catch in your voice, actually, that you thought the testimonies were powerful.

I'd like to pay tribute to the powerful way you have expressed your views to us this afternoon and this morning and, in particular, what has impressed me is the way in which you have seemed to understand the reasons for others' behaviour in what you've said. Searching, as I see it, for a reason. You have enlightened us, I think, in a number of respects because of the different, slightly different take, angle that you have on the events we've heard about from that of many others.

And so you've told us that stigma has not only affected those who have been infected directly, in the way in which people in society generally have approached them, but also affected those who treat them, in the treatment they got or rather didn't get.

You have put in a powerful plea for the treatment by the specialist who is the true specialist, as opposed to someone who doesn't want to

let go of their patient.

You've curiously, though you are a doctor, because you have a PhD, you have been able to educate doctors who are clinical doctors and others. You describe yourself as a treatment activist, and you've enlightened us again about the ways in which you have been able to educate those who are in clinical authority, that's probably the best way of putting it, and nurses, and told us as well what it was like, what it felt like personally and for others, to be a registrant or beneficiary, or whatever word was in vogue at the time, for the Macfarlane Trust, particularly in those early years about which we haven't heard an awful lot of evidence because people have moved on.

So I'd like to thank you for that powerful evidence which you've given today, taking full advantage, I'm glad, of what you see as a human right to give your -- state your case in your day in court, if you like, as you would wish inquiries would give, generally, to those most affected by what has happened.

A. Thank you.

SIR BRIAN LANGSTAFF: So thank you.

Tomorrow, we have Bruce Norval, do we?

MS FRASER BUTLIN: We do, sir.

SIR BRIAN LANGSTAFF: Ten o'clock. Ten o'clock tomorrow.

(2.23 pm)

(The hearing adjourned until 10.00 am the following day)

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