Thursday, 10 October 2019

(10.04 am)

SIR BRIAN LANGSTAFF: Today is one of those days in which all the witnesses are anonymous. Let me say something largely for the benefit of those who may at the moment be watching online and it's this, that in the hearing room you will see and hear the witnesses. There will not be any live stream visually of our first witness. He will be known as Paul.

Then after the break AH, as he wishes to be known, will be known, will give evidence from outside the room. You will not see him but you will hear his voice. Those who are remote from this hearing room will have neither. There will be no live streaming.

There will be no live streaming either of our third witness, who will give evidence in front of you, but whose voice will not be simultaneously transmitted around the country.

It doesn't mean that their evidence will simply disappear and not be recorded for the benefit of the public so that they can follow this Inquiry. A transcript of the evidence that each gives will be provided later.

So slightly different arrangements for each of the three but we start, if we may, with Paul and in

his case let me read out the restriction order and bear in mind what I said at the start of this set of hearings.

It is so easy to think you have heard it all before and not to take notice but it is important to each of the individuals concerned as it is to all who have asked for and been granted anonymity and it is important that they should feel as comfortable as they can be in giving evidence which is, as those of you who have done it will know, those of you who have yet to do it will anticipate, is not at all easy.

So the order in his case reads as follows: I order that the name and address of Paul, the name of any other member of Paul's family and any other identifying information such as Paul's image or a description of his appearance cannot be disclosed or published in any form unless express permission is given by me or by the solicitor to the Inquiry acting on my behalf.

Witness W1003 -- numbers become quite important today because each has a number -- witness W1003 must be referred to only as Paul. This order remains in force for the duration of the Inquiry and at all times thereafter unless otherwise ordered and I may vary or revoke the order by making a further order during the

course of this Inquiry.

I need not remind you but anyone else who may be listening, breaking that order has serious consequences. Please don't go there.

So Paul.

PAUL, sworn

Questioned by MS RICHARDS

Q. Paul, you have severe haemophilia A.

A. Yes.

Q. During your childhood you received cryoprecipitate but you developed inhibiters. Can you just tell us a little about that.

A. Yes. I was diagnosed with haemophilia after about a year/18 months. I've got no haemophilia in the family. I'm a genetic mutation so I was the only one. I started cryo I think about '66 when I was two or three years old. It was evident quite early on that I had inhibitors or resistance to it so basically my body was rejecting the clotting factor my body was missing in the first place.

Treatment was given though only for essential bleeds and their thinking was because of the inhibitors they would only give me cryo when I really needed it because every time they gave it me my inhibitor levels would raise, so it was treatment only

when it was really necessary.

Q. For that reason, you were generally treated with bed rest, ice packs, splints analgesia and gentle physiotherapy for a large part of your childhood.

A. That was most of how my bleeds were treated, yes.

Q. One of the points that is important to you, as I understand it, to make is when you needed treatment it was not for life-threatening reasons and this was not life-threatening, the life-saving treatment that you were receiving?

A. No, my whole life I've never had a life-threatening incident. I've never had -- I'm very lucky in that respect. I've never had appendicitis or a car accident or anything like that. All my bleeds have been in my joints, my knees, ankles, elbows. So all the factor I was given was just to stop the bleeding, to just basically stop joint damage. But I did have a lot of joint damage as a kid.

Q. From 1974 to 1976, and the significance of 1976 will become apparent in a moment, you didn't receive any cryoprecipitate at all. You were just treated in this rather more gentle and restful way that you have described?

A. Yes, that's right. I went a whole two years without any treatments. It was just ice packs, cold water bandages, splints, yes, for that time period. In fact, on one of my notes in my medical records it says only dare to treat Paul in the event of a life-threatening bleed. So I didn't have any treatment at all for a few years.

Q. You've produced a letter written by your father in March of 1975 and we're just going to look at that letter and what prompted it.

Paul, it's 1003017, please.

It should come up on the screen in front of you. You will see it's addressed to Dr French who was your haematologist. It is dated 2 March 1975. It says:

"Dear sir, I am the father of Paul. Having observed the public interest lately in the blood extract Factor VIII, I find the article published in the Sunday Times page 3, February 16th, 1975, most disturbing. I've raised monies by charity organising in the past years for haemophilia research in the hope that one day haemophiliacs could be helped, if not 100 per cent, even 50 per cent. I'm writing to you after having thought deeply about this article to ask your [and then there's some words unclear] opinion regarding any personal help if possible for Paul. I would be willing to spend monies I have available to ensure a less painful way of life for him."

That's a letter your Dad wrote.

A. Yes.

Q. It was prompted by an article he read in the Sunday Times and we've got that article.

Paul, could we have the Sunday Times article up please. Thank you.

So we can see it's dated 16 February 1975. It talks about a particular child, not you, with haemophilia and it then goes on to discuss the question of Factor VIII products.

If we pick it up in the left-hand column, Paul, please, towards the bottom of the page it says this:

"Little Factor VIII has been made in Britain partly because the Department of Health was unwilling to put up money for processing facilities and partly because blood is scarce and a large quantity is needed to make a little extract. Other countries however have been making Factor VIII. It is available under the health schemes of many European countries. In 1973 the directors of British haemophilia centres, annoyed that many British patients were not benefiting from Factor VIII began to put pressure on the Department of Health", and then it refers to two drug firms being licensed to import 10 million units of the extract from America and Austria, enough to treat all Britain's haemophiliacs for several months but then refers to there being a snag in terms of the funding of that.

Then if we pick it up, please, Paul, third column, again towards the bottom of the column:

"Last year, the two drug firms stuck with a large stock of Factor VIII with a limited shelf life started to re-export and protested strongly to the Department of Health. It responded last October by buying 500,000 units of Factor VIII from the companies and then offering it to the regional health authorities at the normal commercial price. What this was intending to achieve is uncertain, nor is it known whether all the material was brought up. A senior official at the Department of Health said it was certainly not purchased for the exclusive benefit of haemophiliacs. It may have been to promote good will towards the drug firms."

Then it refers to the department having since licensed two other firms.

Then there are two quotes from a Dr Letsky at Great Ormond Street which, Paul, you have drawn the Inquiry's particular attention to. The first is this: even the famous Great Ormond Street Hospital in London is so short of Factor VIII that it cannot give John's [that's the child referred to in the article] mother a few days supply for use at home. John will undoubtedly be permanently crippled unless he gets home treatment with Factor VIII soon says Dr Elizabeth Letsky who treats him. If we had sufficient Factor VIII a bright boy like John could become a valuable member of society, but if he has to continue this way, coming in five or so times a week after an hour's journey he is in danger over spending his life in a wheelchair and becoming a burden."

Then there's reference to Lord Owen and a pledge of £500,000 to improve the blood transfusion services and then in the right-hand column we see this:

"At present, most National Health haemophiliac patients are treated with a crude blood product called cryoprecipitate."

Then it says this:

"This contains many impurities which makes it dangerous especially for children, Dr Letsky says. 'Each time I inject a child who is allergic to cryo I have a sinking feeling. I never know whether he will develop a serious reaction. There are no such problems with Factor VIII.'"

That's the Article that unsurprisingly prompted your Dad to write to your doctor to say, "Is there something that can be done for my son"?

A. I mean, I've only, as you know, I've only seen this article this week as the Inquiry team was trying to locate it. Yes, it says "cure". It says "cure" at the top in the headlines. Any parent of anyone with haemophilia, it's going to attract their attention. If they've got a senior doctor saying there are no such problems with Factor VIII it's going to obviously attract interest in using the product.

I think as well one of the most important things of this article that I mean, it's obviously '75 so looking back, the whole article is about if you don't have Factor VIII, it's crippling, wheelchair, unfortunately being a burden on society. There's only a little comments from Dr Rizza that mentions life-saving and, as I say, for most people with haemophilia, most bleeds, about crippling, are about joint damage, about muscle wasting. Without Factor VIII we would have undoubtedly all of us ended up in a wheel chair and probably been a burden, but how many people actually have life-saving treatment with Factor VIII is probably quite minimal.

Q. Just for the sake of completeness we will look briefly at Dr French's reply to your Dad. Paul, it is 10031003, please.

It says -- it is dated 6 March '75:

"Thank you for your letter about the question of Factor VIII concentrate. As you say, this is causing a good deal of public concern, which as a doctor who has to treat haemophiliacs I welcome. The question is one of money which as always is in limited supply and of how best to use the money that is available. Very strong representations have been made in the medical press and elsewhere by doctors seeking to make Factor VIII concentrate more readily available for their patients."

Then he goes on to talk about, in your case, the issue in relation to the inhibitors and only daring to use Factor VIII to treat you in the event of a severe possibly dangerous haemorrhage.

A. Yes.

Q. So that was the position in 1975 but the treatment you received changed in 1976. We'll look at some letters in a moment but can you tell us what was the change in 1976? How did you come to receive factor products?

A. There was two instances really. One of them was my parents attended the World Haemophilia Congress that took place in that year and Dr Charles Rizza was giving a talk on the use of Factor VIII, promoting the use of Factor VIII for patients with inhibitors.

Obviously having been told in the past I wasn't able to have these treatments to have a senior doctor then say that they are now finding that there's benefit obviously my Mum and Dad -- I mean, I was 11 at the time -- they were obviously don't like to see me in pain, which I was obviously in a lot of pain at the time with bleeds that were being untreated, this was an option to move we thought at the time.

Dr French made a referral to Oxford and I do actually remember going down with my Mum and Dad to see Dr Rizza who basically put forward a programme for me to start using Factor VIII as home treatment. I think it was recorded that I was one of four patients in the country at the time with inhibitors on home treatment. So, yes, it was what we thought was cutting edge I suppose at the time. I remember feeling very happy to be having something that was, yes, helping my joint bleeds and not having so much time on the sofa or in hospital.

Q. So your treatment switched to Factor VIII products. As far as you're aware, were your parents ever told of any risk of infection associated with the use of factor products?

A. Not at all.

Q. We'll just have look at some of the correspondence.

Paul, could have up on screen, please, 1003007. This is a letter of 17 June 1976. We have actually only got the first page here but it is from Dr Rizza to Dr French. Dr Rizza has seen you in his clinic. If we pick it up in the third paragraph, please, it says:

"I see from your letter that Paul has not had a dose Factor VIII since 1 January 1974."

Then the next paragraph says this:

"I've had a long talk with [that's your parents] about the prospects of home therapy. They are both very keen for Paul to have it. Paul himself likes the idea."

Then it says this:

"I think it would be wise to try as far as possible to treat him with the NHS concentrates and I would suggest that you get in touch with Dr Maycock, Lister Institute, to see if he can supply you. Failing that, get in touch with me again and I will see what we can do from this end. As a last resort, I think it might be justified to put him on to one of the commercial Factor VIII concentrates and I would suggest Kryobulin, the material made by Immuno of Vienna."

There's a number of references in your records around this time in the correspondence to the fact that you should be treated with the NHS product and with a commercial product only being used as a last resort.

Do you know why that was being said?

A. It doesn't say, does it? It doesn't say. No, I mean, I'm looking back, I mean, there was nothing to say that because one was safer than the other. I just probably presumed it was about cost, yes, because like the Article in the Sunday Times was all about cost and money. I think I do remember the doctors talking a lot about the cost of the treatment. That was always mentioned on the wards and in the clinics as a reason for not having -- and to use your Factor VIII responsibly because of the cost. It was always the cost not the safety. So, yes, I can see why now looking back but at the time that wasn't obvious.

Q. We can just look at the letter that was then sent from your consultants to Dr Maycock with the request following on from Dr Rizza's suggestion.

1003006 please, Paul, 21 June 1976. We can see it is Dr Blecher writing to Dr Maycock at BPL in Elstree saying this:

"The above lad is a haemophilia patient of ours who has developed a Factor VIII inhibitor. In discussing his case with Dr Rizza recently, Dr Rizza

mentioned that at Oxford nowadays they are treating such patients who have inhibitors with frequent and regular Factor VIII therapy and obtaining good results. He recommended that I place Paul on weekly prophylactic Factor VIII therapy."

So there were two changes to your treatment regime at this time, first that you were moving to use the Factor VIII products but, secondly, it was going to be given to you prophylactically.

A. Yes, it was but I think actually looking back at my records there wasn't enough factor consumed for it to be once a week and I think it probably was more on demand but, yes, it was suggested I go on it prophylactically.

Q. The letter continues:

"It would be obviously be preferable to use the NHS concentrate."

Again, as you say, it doesn't explain why that is seen as obviously preferable?

A. Yes, obvious to who? Not to the patients or the parents, I think.

Q. Then lastly in terms of the correspondence in June can we have up 1003005, please, and again we see this is a letter from Dr French. It's to whom it may concern and if we look at the body of the letter, please,

Paul, again it refers to you having been seen by Dr Rizza and then it says:

"The Factor VIII preparation preferred is NHS concentrate from the Lister Institute or that prepared at Oxford. Failing this, the commercial Factor VIII concentrate might be used."

Then we can see, please, Paul, at 1003004, this is a letter September 1976 again from Dr French and we can see from the last paragraph that by this time, September '76, your parents had been trained to give the doses of factor to you so that you received treatment at home.

A. Yes.

Q. One of the observations -- or you have, I think, an observation to make about the use of home treatment as an idea, as a concept.

A. Yes, I spent a lot of time off school and all the rest with bleeds that weren't treated so actually having the treatment was better for obviously I wasn't spending as much time in pain. I was having more of a fruitful life suppose. But the thing is with home treatment everything was talked about the cost. When the doctors were giving home treatment, the treatment was taking place in your own house, in the kitchen, whatever.

If the doctors knew, you know, obviously, use NHS not commercial, if they are saying things like that, if the doctors did know there was a risk I think it was almost like they didn't have to see the risk. That risk was out of their vision. It was being done in my house. I don't know whether they would have felt differently if they were injecting it into my veins, if they knew it was risky.

It was almost like, well, we're not seeing it so we don't have to deal with it and then the patients at home, myself, we weren't aware of any risks. I actually remember thinking it was great that I'd actually got things -- well, later on I ended up on commercial products. We'll probably talk about that later, but yes. It was great for us but I don't think the doctor -- I think there was, yes, a discord between the risk factors and what we knew at home and because the doctors weren't seeing it they didn't have that responsibility. That's only my thoughts.

Q. You said in your statement you were treated prophylactically as far as you know from your records from the summer of 1976 to April of 1977 but after that you were treated on demand --

A. More or less, yes.

Q. -- when you had a bleed.

By the end of 1976, despite what had been said in the letters that we've seen and for whatever reason, you had started to receive the commercial Factor VIII products rather than the NHS products.

A. Yes, and I don't know why that was, whether that was a financial thing, but we go from letters in June and doctors' notes in June saying, you know, NHS Elstree products, you know, and the last result commercial products. That was documented in September '76, but by December '76 I was on American commercial products. It was only a three month difference, so we had gone from, yes, one extreme to the other really.

Q. We've got a list of the products that you had from 1980 onwards in your witness statement and we'll just call up that list, please.

Paul, could we have Paul's witness statement up, please and we'll go to the second page.

We can just see here this list. It gives us a sense of it, from 1980 onwards you've got Koate, Kryobulin, Huminate, there's then in '81 the NHS product being given, then Factorate, Koate again, Kryobulin, Factorate. In 1982 you are recorded as having Hemofil and so on. We can see from that the majority of products you received during that period were the commercial products with you only

occasionally receiving the NHS product?

A. Yes.

Q. Was there ever, as far as you know, any discussion with your parents about that change or any reasons for it?

A. No, only financial. I think it was probably some products were cheaper for the hospital to buy in. Yes, there was -- I mean, something significant changed in 1977 for this but -- no, it was anything and everything. I remember having porcine factors at one point but my factor records were a bit sketchy really what I've received from the UKHCDO on my files.

Q. It was in April of 1977 you developed acute hepatitis B. What can you recall about that?

A. Having had my first commercial Factor VIII in December which I think the Cutter product was mentioned in my notes. Yes, by April '77 I had Hep B, I had nose bleeds, I was losing weight, I was jaundiced in colour and, yes, they diagnosed me as having hepatitis B. I was told I was very unlucky. Yes, within four months of having my first commercial factors I'd got a strain of hepatitis.

I remember it being a very strange time because I was aware of my haemophilia at that age, it was all I'd known from growing up, but this was something

different, this was. It sort of changed things a little bit for me inside and I think the family as well because they treated it like it was something serious, the whole family, my Mum and Dad, my brother and sister, they were all blood tested to see if they'd got it. I remember having to have separate towels, face washing cloths, mugs, knives and forks. Everything was -- I was treated separately for a point of hygiene really and I was aware that something was dangerous with the blood.

I had the hepatitis B in the acute form, not the chronic, so I actually displayed all the symptoms very readily and I was ill for a couple of months and sort of, yes, I was young. I was 13 at the time. I bounced back from it. I thought I'd been unlucky. I was told I was unlucky and that was my experience of hepatitis, yes. You go yellow, you don't eat your food. I lost weight. Couldn't eat anything fried for a long time. I think one of my doctor's notes says, "Keep Paul on a bland diet", and that was more or less it really.

Q. In terms of risk, you were, as you say simply told, your family was told you had just been unlucky.

A. Yes. Well, if it was anything more serious I suppose that was negated by the fact that they continued

putting me on the same factor products that I was using before having Hep B, so they didn't like stop my treatment. I still continued to use commercial products after that because I had just been unlucky that time.

Q. We can see from your records, I won't call them up on screen but you referred to them in your witness statement and we have them, that not only was your family test and you were given advice about having separate utensils and so on, but that also action was taken by your doctors to write to the manufacturers of the products that you had been receiving to report a possible problematic batch.

A. Yes.

Q. You have contrasted your experience in relation to what happened when you had acute hepatitis B with what happened eight years later when you learnt of a further infection.

A. Yes.

Q. We will come on to that. You recovered, in any event, after a few months from the acute hepatitis B.

A. Yes.

Q. Then you have recalled in your witness statement in around 1983/1984 becoming aware or your family becoming aware of the issue of AIDS and you refer to a World in Action programme.

A. Yes.

Q. What do you recall?

A. I think the first time we were alerted. I mean, because I had had the Hep B I was aware and my family was aware there was a risk of something. But, as I say, that risk of the hepatitis was me being ill for a couple of months and if that's the most dangerous thing, then if the Factor VIII is actually reducing my pain, helping mobility, helping me have more of a normal childhood then I think you sort of weigh those risks up, don't you.

When the World in Action came out, obviously it alerted us. My Mum and Dad were members of the local haemophilia group. I think they had had a phone call to say something's on the telly and we watched it. I remember watching that. I think my next appointment at the doctors I think they played it down. I remember them playing it down. I remember them saying it was sensationalised and all that, "Oh, that's not going to be happening in England, in Britain, it was a sensationalised television programme". The doctors seemed quite happy to keep prescribing me the Factor VIII so, you know ...

We did have, like a lot of people who have sat

in this chair, trust in doctors. I mean, because of the nature of haemophilia you were a patient your whole life. It wasn't a one-off so you had a relationship with your doctors. You saw more of them than you did members of your own family, so there was trust there. So when the doctors said, "This television programme's sensationalised. Don't worry about it. Carry on taking the factor", yes, we did.

Q. You have said that the other source of information for your parents as well as the doctors who responded in the way you have described was the Haemophilia Society and you've referred in your statement to some specific leaflets that were disseminated by the Haemophilia Society at the time?

A. Yes, the Haemofacts.

Q. You have quoted from a couple of them. We have the actual leaflets, so we will just have those on screen.

Paul, could we have 1003018.

We can see here the date of it. This is Haemofact AIDS release number 3. It is dated 11 May 1984 and if we go over the page, just in the first and second paragraphs it refers to -- so it's described as:

"Acquired immuno deficiency syndrome, an update.

"The occurrence of acquired immuno deficiency

syndrome, AIDS, in haemophiliac patients has strongly suggested transmission of this disorder by blood products and epidemiological studies have suggested it may be related to a transmissible agent."

Some further information given about work being undertaken in America and in Paris. It says:

"These reports should be received with optimism. Obvious benefits from such findings would be the provision of a blood test for both affected persons and donated blood and in the long-term the development of a vaccine. In Great Britain the number of haemophiliacs who have been reported with AIDS remain at two, thus the incidence is less than 1 in 1,000 patients at risk."

Then there are a number of other observations and if we just go over the page, please, we can see the author of this, it would seem, is CA Lee senior registrar at the Royal Free, Dr Christine Lee.

That is the first leaflet you have referred to in your statement. We will just look at the second and then come back to your evidence about it.

Paul, could we have up on screen, please, 1003019.

This is the subsequent release, release number 4, Haemofact AIDS, 24 September 1984, and then

over the page we can see this is authored by Dr or Professor Kernoff, again from the Royal Free:

"The possibility that the acquired immuno deficiency syndrome, AIDS, may be caused by an unusual virus has always been a strong one."

Then again it refers to the work being undertaken in France and the USA to isolate the viruses. That is described in the next paragraph as a major step forward, suggests that tests may take some while to be developed. Then towards the bottom of the page, last five lines, it says this:

"The presence of antibodies implies past exposure to LAV/HTLV-III but this in itself isn't too surprising. Most haemophiliacs have antibodies to a variety of different viruses in their blood, probably as a result of repeated exposure to small amounts of these viruses in transfused blood products. The presence of antibodies [top of the next page, thanks, Paul] is usually taken as evidence of immunity to infection and perhaps one reason why the risk of AIDS in haemophilia is so low, around 1 in 1,000, is that many patients are immune to it."

Then it goes on to say there are probably other reasons too and then there's a reference in the next paragraph to AIDS being:

"... a relatively new problem for haemophiliacs but infection with hepatitis B virus being an old one which is fast on its way to being solved."

Then we've got, for the sake of completeness as part of the documentation from you, the follow-up leaflet but I don't think we need go to that for present purposes.

What you have said in your statement about these leaflets is that they provided a further degree of reassurance to your family because they essentially gave the impression that the risk was a very low one. Is that correct?

A. Yes. I mean, it's in black and white there. My Mum and Dad got a lot of information from the Haemophilia Society. They were active members within the Haemophilia Society. These are the information leaflets. I didn't actually see these until some years ago. My Mum had actually kept them. I think she kept them because after they realised I had been infected with HIV that it was something tangible to hang on to, to sort of say, "Well, we weren't making a mistake. We were trusting the doctors".

Not only were they trusting the doctors we saw in person that were still administering the Factor VIII and sending it to my house for us to use

at home, but the information that was coming from the Haemophilia Society which was and has been the only really information source and support for people with haemophilia, in two separate articles they are saying the risk is 1 in 1,000, saying the incidence is low. They are saying that we might have antibodies that will actually protect us. It's quite -- well, it's bad enough if 1 in 1,000 get infected with HIV but it was almost like if that's the only risk we've got is 1 in 1,000 people probably took that risk because they didn't really know the implications of HIV at the time and nobody was -- nobody was saying don't use it. They were saying continue.

I mean, this other article that we've not discussed that was -- at the same time there was the -- Peter Jones had got the booklets AIDS in the blood and there was a question in that was about "Should stop my factor treatment", and he says no. I think it says something along the lines of there would be more damage done from not treating bleeds than there ever would be from any possible risk of HIV transmission.

We went from I guess, I say guess, whether they worked that out I don't know, but from 1 in 1,000 it actually turned out to be 33 per cent, a good third of

us ended up with the whole ...

Q. What you have said in your statement with this information from doctors and from the patient organisation and, of course, the Haemophilia Society leaflets that we've just looked at, what they are based upon is advice from, it would seem, the doctors there named. It says:

"No-one was saying anything different. We accepted the risk was minimal."

Then you say this:

"My doctors were still advising continued use of factor concentrates, even advising me to take factor more regularly on the same day that I was unknowingly tested for HTLV-III."

Can you just expand on that last point, please, Paul.

A. Yes, this is something when I got my medical records back that I really did look through with, yes, more of an inquisitive eye, I suppose, really. I had a group -- I know it was 19 April, I remember from reading my notes, 1985, that my notes in the doctor's records from the actual appointment of a normal clinic check up appointment, I was still having lots of internal bleeds in my left knee, is asking me basically to take Factor VIII on a more prophylactic

basis and to undertake some gentle physio or, if I am going to do anything physical, to take the Factor VIII prior to doing any physical exercise, so they are actually telling me to use more Factor VIII.

It's been said time and time again during this Inquiry from people with haemophilia that when you go for your clinic appointment they take bloods. It's just part of the routine, and with me they always checked bloods for my inhibitor levels and they'd check platelets and full blood counts.

What I didn't know that day was they were also testing me for HTLV-III. There's no mention of it in my notes. It wasn't discussed with me. I didn't know they were testing for that. There was no mention of it.

Q. If we can have up on screen please 1003 --

SIR BRIAN LANGSTAFF: Just before we go there, can I just take you back to the Haemofacts 3 and Haemofacts 4, 18 and 19, first of all, 18.

Did it ever occur to you that Dr Lee in the first might be using the word "risk" in a different sense from the way that Dr Kernoff appears to have been using it in the second?

Look at the first. It's number 3. It's the page before. Just pause there:

"In Great Britain the number of haemophiliacs who have been reported with AIDS remain at two, thus ... [I am not quite sure it follows but] ... thus the incidence is less than 1 in 1,000 patients at risk."

So she is talking there about incidence.

If we look at the Kernoff letter which is number 4, thank you, can we look at the --

MS RICHARDS: Second page.

SIR BRIAN LANGSTAFF: Second page, thank you. It is the bottom of one page and the top of the other, the bottom of the screen:

"The presence of antibodies taken as evidence of immunity of infection perhaps one of the reasons why the risk of AIDS in haemophilia is so low ..."

So that's talking about the risk in haemophilia whereas the first one is talking about the incidence and incidence and risk might be thought of as two separate things. So when Dr Lee is talking about incidence it's incidence of those who are at risk, in other words, every 1,000 people at risk 2 get full-blown AIDS. This is talking about the risk of -- in a population and it may be two different things.

MS RICHARDS: Yes, of course, you, Paul, were a teenager at the time.

SIR BRIAN LANGSTAFF: You wouldn't have looked at it that way I suspect, you just saw the two figure, but you took it that you had a very low risk.

A. Yes, I think anybody else that was probably reading those information leaflets would have read it the same.

SIR BRIAN LANGSTAFF: I think we can explore this later.

MS RICHARDS: Absolutely, sir. Certainly I think we have the potential to do so with at least one of the authors.

SIR BRIAN LANGSTAFF: Yes.

A. No, I never looked at it like that.

MS RICHARDS: Just picking up upon the reassurance that your family may have placed upon this, you found I think these leaflets in your Mum's bedside drawer. She kept at least one of them you have said in her bedside drawer until the time of her death.

A. Yes, my Dad gave them after my Mum had passed away. She kept them all that time. I hadn't seen them until -- you know, it was 20 years ago now.

Q. Returning to 19 April 1985, you went along for a clinic appointment. You were encouraged, as you say, and we don't have the record in the documents here but the record absolutely says this, to use Factor VIII and bloods were taken. As I understand your statement you were not told that bloods were being taken that day for the purpose of testing for HTLV-III.

A. No. There was nothing in the records. I would -- it's the sort of thing that I think you'd stick with you. No, I had no idea that's what they were doing.

Q. We'll just put up on screen the test result. It's very faint but it's 1003014.

The date taken, it's not very clear on this but actually it is possible to see it on the underlying documents and we've looked at them, is 19 April 1985 as you have said and the test result says this:

"Antibody to HTLV-III present."

Now, I want to talk next with you about how you learnt of this test result. That was 19 April that the bloods were taken. You then received a letter in June. We'll just look at the text of that, 1003015, 24 June 1985 from Dr Blecher. It says this:

"Dear Paul, I've now received the results on all the tests we carried out on your recent blood samples, including one result I have only just received from a specialist laboratory in London. I should like to briefly discuss one or two of these results with you personally. Could you therefore please come to see me for a short time one day next week. Please telephone my secretary to arrange a time convenient to you and during my working hours."

You make some observations about that letter in your statement. Perhaps you could tell us what those are.

A. There's only one paragraph and yet it says an awful lot to me now. I mean, the specialist laboratory in London. I don't know where that was, and that's quite an interesting thing in itself now looking back. But he wanted to briefly discuss the results with me and the appointment was only -- make an appointment for a short time. There didn't seem any urgency to it.

"Phone my secretary to make an appointment." The fact that he briefly wants to discuss something with me and he only wants to see me for a short time, to me, at the time, that said to me that wasn't very important. It was going to be something that was -- it was a brief chat. Why would you have a brief chat to tell somebody they've got a terminal illness? It wasn't for my benefit and just -- yes, I just think that was very, very poorly thought out.

I was working at the time. I was 21 years old. I just basically asked my boss if I could have a short time off work. I'm going to go to the hospital. I've got an appointment. I'll only be a hour or two.

I may well even work through my lunch hour or something to cover it or something that day. I can't remember, but I remember the day, the afternoon, very well when I went for that meeting, which was, yes, I think early July when I found out.

So they took the bloods in April. They wrote to me the end of June. I went for the appointment in July. I didn't actually see Dr Blecher who wrote that, I saw the other of those two doctors.

Q. Dr French you saw.

A. Dr French, he saw me. He didn't make eye contact with me, just looked up and down. It was all very strange because I was very used to going to the hospital, like all the other people with haemophilia, very used to going to the clinics. I went to the normal clinic and I was told it wasn't there today. It was somewhere else, and I was then told to sit outside.

I was on the ground floor in a corridor, which was a main thoroughfare. There was just a seat, one seat outside. It was a room I had never been in. It was like a storage cupboard. I think the alarm bells started to ring a little bit at that time but even then I didn't expect anything like that that day. He wants to see me for a brief time to discuss something that's only going to take a short moment.

I walked in the room. It was a windowless room. I just remember there being some filing cabinets, one desk with a chair one side where the doctor was sat and me on the other side. I remember him telling me they had taken some tests for the HTLV-III. I had antibodies to the HTLV-III. I asked what the HTLV-III was. He said it was the virus that causes AIDS. I actually, do remember in my naiveté at the time saying, "I've got antibodies to it. Does that mean I'm protected against it?" And he said that the antibodies in this case meant that I'd actually got the virus present in my body.

I remember him asking me if I'd got any questions. I hadn't got any questions because it was just -- I was just like I think a rabbit in the spotlights then. If I'd been told in April that I was having this test done I would have had time to actually think about it. If when the letter came it had given me a bit of indication. If it said, you know, take the afternoon off, bring somebody with you or whatever, I might have thought it a bit more serious.

It seemed a very surreal moment that I was being told. I remember him saying to me the only advice -- I didn't have any questions. He told me I probably

would -- the HTLV-III virus would probably manifest to full-blown AIDS in I think he said two to four years, don't have sex. If you do only wear a condom.

It all seemed very strange because that was it. I was asked, any questions. I didn't have any questions, go. I remember even standing in the corridor thinking did that really happen. I went back to my car, sat in the car park. I just sat in my car for a while thinking did that really happen, running through, trying to run through what he said, trying to make sense of it all, expecting something, follow-up and there was no follow-up.

When I look back to when I was infected with hepatitis B in '77, which was eight years earlier, I was told, I was given -- well, the family were given advice then, you know, about the transmission possibilities. We were told about face cloths and towels and cutlery and all the rest and I was given no advice with this at all. I wasn't given any advice -- I'm sorry, it wasn't just, "Don't have sex, wear a condom". It was, "Don't have sex, wear a condom, and don't tell anybody". That was reiterated very strongly, "Don't tell anybody".

I went back to work that afternoon because I thought I would be in trouble with the boss if

I took any more time off because I said I'd only be gone an hour or so, so I just pretended that everything was normal.

Q. You have said in your statement you remember thinking it was odd that they didn't ask for your girlfriend at the time or your parents or siblings who you were living with to be tested, again contrasting that with what happened when you had the acute hepatitis B eight years previously.

A. Yes. Okay, this is where my head -- my mindsets at the time. When I had Hep B which I was ill with for two months, all the family were tested to see if I had passed it to them. When I was given the HIV diagnosis, nobody was called in. So, in a way, that gave me a false sense of security that maybe -- or maybe it's not so bad. If it was really bad, well, maybe it's not as bad as the hepatitis B was. It was very confusing.

Q. You have described it in your statement as the briefest, most unprepared and most uninformed appointment?

A. Yes. I had no preparation for it. They knew what they were going to tell me. Because they knew what they were going to tell me, I mean, looking back at it they should have prepared a lot -- they should have known that telling someone -- yes, telling someone, those doctors had treated since I was a toddler. They'd known me. They know my family. They knew what I was like and everything. They just saw me for a few moments, gave me the most devastating news I'd ever had. Told me that I've only got a few years to live, telling me to keep it a secret. Everything went out the window that day. Everything changed that day.

Q. You were, as you say, 21 years old. You've said in your statement you "had the world at my feet"?

A. I thought I did.

Q. You had a good job, a girlfriend, an active social life, but on that day your life changed forever.

A. Yes.

Q. You still thought you were one of the unlucky ones, you were the 1 in 1,000.

A. Oh, yes, that was the other thing. I didn't realise how deep this was because they called me in and I had been given this and I was told not to tell anybody. I was unlucky to have the Hep B. I thought I was unlucky to have the HIV. I just -- because of all the literature was saying 1 at 1,000 in risk I just thought I'd been really unlucky, that was all. I just thought, well, you know, life is life and some people are luckier than others and I just thought, yes, I was

just drawing the short straw every time and that's what I, probably quite selfishly I thought I was just, yeah, one of the unlucky ones. If there had to be 1 in 1,000, I was the one.

Q. Did you receive, following that appointment, which you have described in the way you have, did you receive any follow-up care, any follow-up appointments at the hospital in relation to the HIV diagnosis?

A. Not initially, no. I still went for the normal haemophilia clinics which I think at the time were every six months, which was probably quite normal. No, I didn't have anything -- there's nothing in my notes and there's nothing in my memory that say I had anything up until about '87, which was about two years later.

I was referred then to I suppose it was one of the very early HIV clinics. It was in the same hospital and it consisted of seeing two doctors, one was a chest expert because most of the people with HIV who were developing AIDS at the time had a lot of pneumonia, a lot of chest complaints, was probably the most common, and a doctor from the sexual health clinic, the GUM doctor, and I saw them.

It was good. They talked to me differently. They treated me differently. They gave me a bit more

time to talk about things, but I just basically bottled that up for two years.

I saw a councillor there as well but at that clinic everything was different because it was the first clinic I had been to that -- I think I was the only guy with haemophilia there. It was fairly obvious, to me at the time anyway, that most of the people there were gay guys and all the guys with haemophilia were all tested, children, adults, we were all tested in '85, around '85, without our consent.

They didn't test all the gay guys in the country without their consent. People were getting ill, so in many ways I think a lot of the gay guys were getting iller probably before -- those that were knowingly had HIV were actually exhibiting illnesses and then got tested and then came to the clinics. So I was seeing people for the very first time that were actually ill and that was -- yes, that was definitely a changing moment for the psyche in me that, yes, this is real. This is what I've got. I'm going to end up looking like some of these people in this waiting room. Yes. It was a big dawning for me that was.

Q. Can you --

A. They --

Q. Carry on.

A. They had a councillor there that was part of the team. I remember seeing her. She was a lovely woman but just remember her telling me how brave I was. I didn't come away with anything constructive to use or they didn't allay any of my fears. Yes, but I did feel like somebody was taking that part of my illness a little bit more seriously.

I'd lost my faith in the haematologists at this point as well because the haematologists were putting in the print risks of 1 in 1,000. My haematologists at the hospital were continuing to prescribe me Factor VIII. Risks weren't really being given and then I ended up with the HIV virus.

So I didn't really trust them. I started to mistrust my doctors at that time.

Q. The impression that your statement gives is that a lot of the information and practical advice and guidance that you've obtained since that time has been not from the medical profession but from the gay guys and the drug users and the organisations that were set up to support them rather than from the NHS bodies. Is that right?

A. Yes. The Haemophilia Society had been my mine and my family's source of information about haemophilia. This was different. Where did you go for information about HIV? Well, yes, the organisations that mainly supported gay people gave the information about HIV. So, yes, I think one of my first phone calls was either to the Terrence Higgins Trust or Body Positive.

They didn't have a lot of people with haemophilia phoning them, as was obvious from the switchboard people that answered. There were different questions and I felt that there was some support there and I then started going to HIV clinics in which I had -- yes, I'd befriend people with HIV that were gay guys, not haemophiliacs. So, yes, my sort of support avenues changed quite a bit.

With drug users as well, that probably came a little bit later when -- I'm stepping ahead but I know you will come back to this with my hep C diagnosis, because at the time it was the gay guys with the HIV and the drug users with the hepatitis and people with haemophilia we had both, and you'd phone one organisation or get support for your HIV but they didn't really know a lot about hep C at the time and you go to the hep C organisations, people like Mainliners, the British Liver Trust. They weren't all that geared up for HIV because their specialism was hepatitis C. So yes, it was a bit of a run around.

So meeting other patients with HIV and

hepatitis C was great for me because, yes, peer support, that peer support, whether they had haemophilia or not, if they had HIV and hepatitis C we had something in common.

Q. I just want to ask you a little about how the diagnosis of the HIV infection affected you in those first years, both mentally and physically.

Start with the mental impact. You talk in your statement about believing you were going to die and being very, very scared?

A. Oh, yes. Yes, it was -- the stigma was intense from all avenues. I think the best advice my doctor ever gave me was don't tell anybody. Yes, you couldn't tell people. People's attitudes to HIV were vile. This inquiry's seen a lot of people's experiences. I'm glad to say I didn't really have any horrible experiences and the only reason I didn't was because I kept it so secret. My family kept it secret; I kept it secret. That day, from that moment onwards, I got very good at lying.

Q. You told people you were one of the lucky ones, that you didn't have it?

A. Yes. Our families, we knew people with haemophilia, you know, my Mum and Dad knew other people and other parents and, you know, you'd probably bump into

someone, "How's your Paul?"

"Oh, our Paul's okay. He was a lucky one." People would ask me, "Have you had this AIDS test thing then?"

"Yes, yes, I'm fine, I'm lucky." I used just to brush it off if people asked. I stopped telling people I'd got haemophilia in case they asked. Yeah, things changed a lot. I became -- I was very, very aware of my mortality, yes. I didn't sleep very well after then. Everything changed. My job went downhill, my performance at work, I wasn't sleeping at night. I'd keep it together all day long, trying to keep a lid of things, trying to keep my emotions, petrified that people would find out. I do -- my -- yeah.

Q. You put it this way in your statement, Paul:

"The thought of dying never left me. I closed my bedroom door at night and my world collapsed. I was very fragile inside by now and would breakdown. I cried a lot at first, always alone and always when I knew it was safe to do so. I had been given this virus and I hadn't been given any tools to know how to deal with it. I kept it to myself and it stewed and rotted me away from inside."

A. Yeah, that's about right and I think that's, yes, the

doctors knew I'd got this. I hadn't been given any mechanisms to actually work it out, apart from me. I had to work it out myself. I just felt so lonely with it all.

Q. You talk in your statement about it being about five years later you were introduced to a psychologist who you felt comfortable with and you started talking about your fears and she set up a self-help group for infected people with haemophilia in your area.

What can you tell us about that?

A. Yes, yes, this was a very illuminating time and a very, very sad time too. I mean, I had had four or five years, five years with the diagnosis at that point, the HIV diagnosis. At that time I didn't find out I'd got hep C until later but the doctors changed at the hospital. The two doctors that had been treating me that have been mentioned so far had both left. We had a new consultant in, a haemophilia consultant. He called a clinic, a new clinic, it was like a review clinic which I thought was great, a new doctor, new start.

That clinic, what was very different about that first clinic was the people in the waiting room. There were people I hadn't seen for years. There were -- because having haemophilia as a kid when there wasn't the treatments around and when I got my inhibitors I would always end up in hospital and my Mum and Dad were members of the local group I knew quite a lot of people with haemophilia in my area and I hadn't seen a lot of them for a long time.

I never really questioned it really but I saw a lot that day, at least four or five of them that I'd known from childhood, from hospital stays in my childhood and it was a bit like a little reunion. It was sort of penny drops, that lot of them didn't look very well and I think the consultant had called a meeting for all the people with haemophilia on his books that were HIV positive.

That was the moment I'd actually realised that, hang on, I wasn't 1 in 1,000. I didn't actually realise so many people had been infected. I didn't realise how many people I actually knew had been infected. It was a bit of a door opening, a light shining that day.

But the consultant, he's still around today, he also invited -- sorry, he was aware that we hadn't, none of us on our records had seen anybody professionally to talk about anything and he had set up a psychologist and at that appointment, as I remember it, there was an opportunity to see

a psychologist. So I saw the doctor, first time I'd seen him, had a review, all the normal stuff, how far can you bend your knee, how far can you bend your elbow, and feeling around my lymph glands and things, and, yeah, I had had a few issues at that time as well, HIV-related with lymph node problems and coughs and colds that wouldn't go away, but, yes, I saw this psychologist. She was great.

It was the best help I had had from anybody at that point. It was the first time I had actually had to talk about it. She was aware that none of us had actually spoke to anybody else about it so she set this little support group up. It was probably 10 or 11 of us, probably all the adult people with haemophilia in the area that were HIV positive. Four or five of them I had known from childhood. It was great at first. It was like we all had an opportunity to talk. We met once a month. It was a basement room at the hospital, again no windows, shut door, no sign on the door. We felt safe in there.

Yes, everybody talked about their problems, everybody talked about their issues. It was incredibly sad, people's stories. However, I don't think I'd be here today if it wasn't for those people because probably in a selfish way I developed those

tools of survival by their problems. A number of them had started AZT. It was all the guys that were on AZT that looked the illest. Whether it was they became ill first and then had AZT but we used to sit in those meetings, it was the guys that were on treatment that were the ones that didn't stop scratching at sores and the ones that were being -- yeah, just showing symptoms of being poorly. We all talked about our illnesses.

There's bits about secrecy. There were guys there that were older than me that had kids. Some of them had told their work employees and their bosses. Everything changed that day, they said. They said they wished they had never told their boss. People stopped talking to them. One guy said that we used to have a canteen in the workplace and it was just mugs. The day after he told his boss he went to work his desk had been moved and all the mugs had gone and paper cups had been brought in, so he said everybody in the office had known.

Kids -- friend's of his children were no longer allowed to come round play. His kids were no longer invited to birthday parties. I realised really how important it was to keep this secret. I might have been at that point, having five years I've lived with

it, at the cusp of wanting to tell people but no, that reinforced the need for secrecy, it reinforced the need to be aware of the medications that were being offered, because at the time the doctors were trying to get me on AZT every time I went for an appointment.

But it was mainly the haematologists, you know. I might have been to this -- I only started going to the GU clinic, which was a sexual health clinic for my HIV, quite sporadically at that time. It wasn't a regular -- the haemophilia doctor was still taking most of my control over my virus. It never really sat well with me but he was, yes -- his specialism was haemophilia not HIV. Just because his haemophilia patients had developed HIV he suddenly hadn't developed a specialism in HIV himself.

So I wasn't a great patient as far as the doctors were concerned because I questioned everything. I was very awkward as a patient but that awkwardness is probably why I'm here today. Probably one of the reasons.

Q. That group that you describe of patients, you talked about people being more ill every month, people getting thinner every month and then the group getting smaller and smaller because people were dying.

A. Yes.

Q. You would be going to funerals.

A. Yes. I knew, some people said I won't be coming again, you know. This one guy in particular, he'd got -- the HIV had crossed the blood brain barrier. He'd started to -- well, he was only in this 20s and he was showing signs of a pensioner with Alzheimer's. He couldn't form his words. He couldn't speak properly. He was very frustrated, very confused. Yes, it was very, very frightening seeing these illnesses and things and, yeah, the group got smaller.

When the group got down to two or three of us there was no real point in having a group, and that was over a three-year period. Weirdly, it was the people that were on AZT that went the first. I think there was one, one or two people alive after that early '90s period as well as myself.

Q. You describe in your statement from those meetings and from watching people getting iller and dying, anger started to grow in you and you started, amongst other things, and we will come to a couple of examples later on in your evidence, but you started, amongst other things, writing to politicians?

A. Yes, that was around the time, round about 1990 when I started going to this group, when I realised so many people had been infected, when I realised, you know,

it was a lot of us that had got HIV and those people that knew, that did make me -- weirdly, I was more probably angry for the people that I knew had been infected than I was myself in a way at the time. It was a very confusing time. My head was full of contradictions. I thought I was going to die. I really did. But on the other hand I thought, no, I'm going to beat this, you know. It's like a Jekyll and Hyde on different shoulders and, you know -- sorry, Jenni, what was the question?

Q. No, you have answered the question. You have absolutely answered the question. The --

A. The anger?

Q. Yes.

A. Yes, I did. I got very angry about it and it did lead to me asking questions, yes, and fall-outs with my doctors and then, yes, somebody must be responsible. I must get more answers.

I wrote to Margaret Thatcher. I mean, I wasn't really that interested in politics as a younger man. I was interested in music and normal things that teenagers and young men are interested in and I certainly got interested in politics after that.

I wrote to Margaret Thatcher quite naively thinking she might be helpful. She didn't reply

herself. It was from whoever replies, her secretary or some civil servant, suggesting that this wasn't -- I haven't got a copy of the reply. There's a lot of letters that I had in the early days that I lost but she suggested that I write to my local MP to bring this up with my local MP.

Well, it just so happened at the time that my Mum and Dad lived in the constituency of Ken Clarke and he was their local MP, so as Ken Clarke had been the Health Secretary and the Minister of State for Health, I thought he would be an ideal person to write to. So after writing to Margaret Thatcher and I felt fobbed off I wrote to Ken Clarke and I actually got quite positive about that. I thought he's the Health Minister. He knows what he's talking about. He's also the local MP. I'll get a response. I did get a response.

Q. We might as well look at that.

A. Let's have a look at that.

Q. It's 021, please. 22 January 1990:

"Thank you very much for your recent letter. I am sorry you are so disappointed by the level of payment we are making to every person infected by HIV as a result of treatment for haemophilia. I do not accept that the infection was the result of any

negligence on the part of anybody in the National Health Service let alone the Government as you claim. This tragic occurrence was the direct result of the emergence of HIV infection in the western world and haemophiliacs needed the best treatment that could be provided in the then state of medical science and knowledge and that was what they received. If any of those affected are able to produce evidence to the contrary, obviously the courts will provide much larger sums by way of compensation. The Government made available the money that we have quite regardless of any question of legal liability. We did so as some expression of our sympathy for those who have been so terribly afflicted by these events."

That was the letter you received in 1990?

A. Yes.

Q. You have, in fact, or someone has written on your behalf more recently to Kenneth Clarke MP and we've got the response to a more recent letter, if we can have the next document, please. We can see it is dated 19 May 2017 and it says this:

"Thank you for your recent email on the subject of haemophilia and the contaminated blood products. I do, of course, recall very clearly the tragedy of the infection of haemophiliacs that occurred in the early 1980s. The lives of many people were destroyed or seriously damaged and every sensible person sympathises with them and their appalling position. I was one of five ministers at the DHSS at the time but I was not the minister responsible for blood products and I did not take any direct part in any of the decisions."

He refers to a Mail on Sunday article and says this:

"I think they are taking an answer that I gave to a written Parliamentary question in the House of Commons. I did answer such questions because the minister responsible for blood products was a member of the House of Lords and a Commons minister had to answer on his behalf in the chamber of the House of Commons. The answer that was quoted was based on the best medical and scientific evidence available to ministers at the time. I am sorry that people have come to believe that there was some sort of conspiracy and a criminal cover-up on this subject. Although not directly involved and with no expertise myself, I think that the haemophiliacs were the victims on the inadequacy of scientific and medical knowledge on the subject of AIDS in the first year or two when it first hit us as a scourge. No-one would have authorised the

continued use of contaminated Factor VIII if scientific advice had been against it. There have already been two full inquiries into the subject which have taken and examined evidence, the most recent was a Scottish one. I think that the Government is taking the view that another public inquiry would not be able to draw on any evidence that has not previously been examined."

Then I think six weeks later the public inquiry was announced.

A. Yes. I had an inkling that the public inquiry was going to be happening. There was a lot of pressure building up, as we all know here it had been coming. I wanted to get in there with Ken before and my letter to Ken was to basically inform him what the Mail on Sunday had said about him and to ask about if he supports the public inquiry and that was his response.

So, yes, although Ken didn't feel a public inquiry was justified I'm glad you did Sir Brian. It's quite poignant that he wrote that just before the Inquiry.

I also think what's also quite poignant, we've got a 27-year gap between the 1990 letter and the 2017 letter and he's almost sticking to the same line, that it was the best scientific and medical knowledge at

the time and no-one would have authorised contaminated Factor VIII, which as we know now there was lots of evidence at the time.

Q. Paul, can I take you back now to the early 1990s. We've talked about the mental, emotional and psychological effects of the diagnosis in those early years. You also over the years experienced a significant range of physical effects from the HIV infection.

You had coughs, colds, lethargy, night sweats, rashes and other infections. What was it like physically for you in those first years?

A. I think the first few years it was more of a mental thing. I think it was just that fear. Well, obviously a fear of dying, fear of dying and getting very poorly, seeing other people with AIDS-related symptoms. None of them are pleasant. They were horrible, horrible diseases and disorders and illnesses.

My overriding concern during all that time which used to keep me awake was the fear of infecting other people. That really I think that was the hardest for me to get my head round. I couldn't bear the thought of passing that on to somebody else and I was always extremely careful with everything. I'd always, just

in case caught myself, I'd always have at a handkerchief in my pocket to wrap around a cut or I'd always have a pack of plasters on me in my pocket or my wallet or things like that. I was always very careful about my hygiene.

I couldn't tell anybody I was dangerous. I used to actually tell people when I had my hep C diagnosis it actually became easier. I don't want to downplay people who have only had hep C because that's been absolutely traumatic for them and has been a horrible, horrible disease in itself, but I actually felt more comfortable telling people I had hepatitis and so I had to be careful with my blood so they didn't find out I got HIV.

That's where my head was at with that.

Q. You learnt of the hepatitis C diagnosis in 1992. How did that come about?

A. Again, a routine clinic appointment and, yes -- I mean, I was reading things about this by then. I was aware from previous conversations with doctors that there was -- in that I'm talking about in the late '80s -- that there was an issue about me having non-A non-B hepatitis. So, you know, I can't say that I was completely oblivious to the fact they had come up with the next letter, C. If they were going to give a name for something that was non-A non-B it was going to be C. I thought that was, you know, wasn't rocket science.

Having had Hep B in the past in its acute form and been ill for a few months with it and bouncing back, I didn't really have that much importance put on hepatitis. So when I was told I'd got hep C and I did ask the doctor at the time what that meant, I was told, "Don't worry about the hepatitis C. The HIV will kill you a long time before the hepatitis C will cause you any problems".

I was even told to have a drink if I wanted to because wasn't sleeping well with the HIV diagnosis and I often, yeah, would have a drink to get myself off to sleep. I didn't drink heavily but, you know, you need crutches and that was one of my crutches, I suppose.

Q. Then you received at some later stage a letter in relation to a possible risk of vCJD, possible exposure to vCJD.

A. Yes.

Q. What can you recall about that and how that affected you?

A. I just, at this point I almost give up at that point, you know, I'd had Hep B, had HIV, had hepatitis C.

I was very, very lucky to still be alive with them all and I have a letter telling me I was -- possible got a risk of CJD. It had all been on the news about the mad cow disease and you were seeing how that was affecting people.

I mean, I was angry at every point but it was anger and despair thrown into one at that point, it was. The letter was basically asking me, like it was to an awful lot of other people with haemophilia here, "Do you want to know if you have had a batch that has been directly implicated with the death of a donor that's been infected with" -- yes, has your blood product come from somebody that has died of CJD? Of course wanted to know.

One of the most important things that I took from the 1980s, the Government's campaign of "don't die of ignorance", I changed that a little bit in my own psyche to "don't die in ignorance" and that's when I sort of set on a mission to know everything. Of course I wanted to know if I had had a batch of CJD blood. I hadn't. It was a relief. My doctors said that I hadn't had any implicated batches but the letter also said it didn't preclude that other people are going to also drop dead in the future of mad cow, CJD, and it did turn out they were on blood donors.

So I was put on the CJD register in Edinburgh. I've never been told I've been taken off that register, so I'm presuming my name is still on there as some kind of risk factor category.

Q. In terms of treatment, first of all, for HIV for the reasons you have already explained having spoken to and observed people on AZT you did not want to have AZT.

A. No.

Q. You resisted treatment for a number of years.

A. And all the following drugs that came up. I mean, when I said I was in the self-help group that was set up that was great. It was proper peer support because that was people with haemophilia with HIV. We had the same issues going on.

Because a lot of them had passed away by the early '90s and then I had my hep C diagnosis by then, I'd also met and was familiar with a number of the gay guys that used to go to the GU clinics. The transition then was to go to one of the local HIV -- well, one of, it was the one, HIV drop in centre.

There was a social worker there. I went because they had a complementary therapist. I used to have a back massage once a month.

It was, yes, I met a lot of people there from

either the drug use past or people, gay people, that had had HIV. They became my support. I think there was only one other guy with haemophilia went there. But, yes, I had a lot of support from them.

That was the opportunity on the coffee table, that's where all the magazines were, all the information about drugs and things. I had opportunities to talk to other people about what drugs they were on, what drugs were coming out. People were very open.

That's when I used to see -- I saw the side effects of the drugs, not those that were getting better, and the earlier drugs in the early '90s were very crude. A lot of them gave lipodystrophy, lipoatrophy, which was like body fat changes. People's appearances were changing. It wasn't just what was going on inside, it was physical on the outside as well. It wasn't just people getting thinner and losing body fat. It was a lot more insidious than that.

It was, you know, but it gave me the tools to talk to doctors in an informed way. I became involved in the '90s in a lot of other organisations both -- well, all really, I suppose got involved with organisations likely Mainliners, who supported people with IV drug issues and probably a lot of the -- involved with things like National AIDS Manual, Community Advisory Board. They were organisations that were putting out information to the HIV community.

It was an empowering time for me because I felt I was taking -- I felt like a bit more of control. But I'd completely lost my trust in a lot of my doctors and I'd lost, obviously lost, complete faith in the pharmaceutical industry. So to go on drugs that they have said been trialled and they are great, well, we've seen in 1975 "the cure" with, you know -- there was no cure. I wasn't going to believe that something had dramatically changed in the way they marketed their products.

Q. In more recent years for HIV you have been in receipt of combination therapy although you have developed -- they have to be changed over the years not least because of interaction with hepatitis C?

A. Yes, yes. I did start on -- oh, I have been very lucky to have lasted until my health got very bad at a time when the drugs got very good and I'm talking about the late '90s, '97, '98 was when I had a CD4 count of about five. The recommended treatment limit was 250. I think the normal ordinary person is around

between 800 and 1,000. I dropped down to 5. My viral load was just going through the roof, up to a million at the time. I couldn't stay awake for more than an hour or two. As soon as I shut my eyes, I just went straight to sleep. I used to sweat profuse within seconds. I had no energy. As I say, sores. All sorts of different complaints I had, and I was still at this point trying to keep a lid on it, keep a smile on my face and pretend to the world that nothing was wrong, yes.

I thought my trying to deceive the public and my friends about my illness was getting a bit thin at that point. It was the time I started telling friends.

Q. In terms of treatment for hepatitis C, that's been a less straightforward path in recent years for you. You didn't want to have interferon because you'd seen, as with AZT, you had seen the effects of interferon on people that you knew and were talking to.

A. Yes. I saw -- I had a very, very good relationship with my hepatologist. We spoke very, frankly. He knew the drugs weren't great but it was all he'd got to offer. We decided between us, which was a great way of dealing with it -- I always felt it was a partnership working rather than a doctor telling me

how to do things -- I just had lots of regular monitoring. I had liver biopsies, ultrasound scans and later in the day fibroscans to monitor my liver.

I cut alcohol out as much as I could. I had a healthy diet. I tried to maintain my liver as strong as possible. I didn't want the interferon because I knew so many people that had tried it and it was horrible for them and it wasn't working as well.

All the data that was coming out regarding co-infection, having hep C and HIV, it was working even less well for people who were HIV positive. So it was -- to go through a year's long treatment that would make me very, very poorly for something that had less than a 20 per cent chance of eradicating it when I wasn't actually ill with it, and this comes back to the point, you know, I have been very fortunate, no, I didn't want it.

When the pegylated interferon came out that was a bit better and I actually thought, well, it sounds a better chance with this and I volunteered to go on a trial for that and I got very excited about starting the treatment because by then I'd realised having co-infection had a co-morbidity effect. People with HIV and hepatitis C were dying a lot faster because the two viruses together were, in the body, weren't

a great mix.

Taking HIV medication at that point I was aware that all that HIV medication was being processed by my liver. My liver wasn't functioning as well because of the hep C. In my mind, my longevity with HIV was to make sure my liver was working as well as it could. So there was a lot of things in the mix at the time.

Q. So what happened with the trial?

A. I got to the week before I started to try it and I was told I was refused to go on it because I had HIV. So I was refused that, to go on that, because they said the HIV would have been a contraindication to the trial status studies, which brings me back to the trust in pharmaceuticals that whenever they have a trial of any type they choose the best cohort of patients for that trial. It's not -- and then when the trial data comes out, the trial data's -- the trial data is set with the best possible group of patients and then its used on everybody. So even if they are getting 60 per cent success rates with the trial data, it's sort of obvious it's going to be 40 per cent or less with everybody that they excluded from the trial.

Again, I was seeing people who had started the pegylated interferon and ribavirin and they were still having side effects, it weren't really any less and the bounce back, people had been cleared and then the virus bouncing back. That psychologically affected people and by this time, I know it probably seems quite fragmented my story, but by this time, when I started going on HIV meds, I thought it was really important that I started touching base with the haemophilia HIV community again. I got very involved with the Birchgrove Group which was the self-help support group set up to support people with haemophilia. It was run by people like me.

It was very powerful part of my life at that point because I did meet a lot of people that -- I did do over the years that were very, very good friends, people had a lot of respect for and, again, a lot of those people aren't here anymore. But it was a fantastic tool for me to educate myself and to be able to educate others too.

Q. When in more recent years new types of treatment became available for hepatitis C, you wanted to receive that treatment but what happened?

A. Yes, I mean, I started hearing they were coming out, I heard they were in trial. I remember going to see my hepatologist and, yes, the first time I've seen him really with a beaming smile on his face. "Right,

Paul, we've got these -- these new drugs are coming on the market. We're going to be getting them soon. Would you like to go on them?"

"Yeah, yeah, great, I'd love to", and then NICE guidelines precluded me from going on them. Because of the cost of the drugs they were only offering them to people who had very bad de-compensated livers. They were offering them to people that were on the liver transplant list. They weren't offering the drugs to people that were well or well-ish with hepatitis C.

So I felt really, really angry at this point because you've got the NHS there that gave me all the three viruses, they gave me the hepatitis C, they refused me going on trials. There was also a point where the drugs were on the market, they were licensed, my hepatologist is saying this is like a completely new revolution in hepatitis C care and treatment and the Government body NICE was saying I wasn't eligible.

So, yes, my letter writing started again in -- yeah, stepped up a gear, let's say that. I spoke to a lot of other guys with haemophilia, HIV, hepatitis C about this as well and I wasn't making any headway with the hospital. So, yes, with help from some other

friends out there who had also done their own bit of investigating I found there was a guy on Facebook in Australia that was selling it over the internet and the clinic in India that was giving the hep C treatment, it was the same agreement they had got here, probably the generic drugs. I went back to my hepatologist and the care team in the gastroenterology department and all I wanted to know from them was if NICE won't finance my drugs, if go to the clinic in India and have it done, which I was prepared to do that at my own expense because, again, with my fears of infecting with HIV, my fears with infecting anybody with hepatitis C were probably greater because hepatitis C is so much more infectious than HIV. I just wanted to get rid of that. I wanted to give myself a clean break with it and I didn't want to be infectious anymore.

All I wanted to know was would the nurses in the hospital in my home town do the monitoring, do the blood tests. I'll buy the drugs off over the internet or I'll go and have three months in a clinic in India but when I come back or when I get them off the internet would they do the blood tests. They couldn't do that because, they said, all the blood tests and all the support were all costed into a course of the

treatment, so they couldn't do one without the other.

So I basically said I would go down this line but -- whether I got heavy handed or not I don't know but I said I'd go to the media. I said if I'm going to do this, if you are going to force me into taking this other route I'm not going to do it quietly. Within a week I had been offered the treatment.

The hep C nurse there and might hepatologists were really pleased had taken that route because it shook things up a bit. Within a year I think NICE had changed their guidelines again and a lot more people were being offered the drugs at that time.

Q. What was the result of the treatment, the outcome of it?

A. I'm cleared my hep C. It was the first line of the oral tablets. They work very well. They were very potent, but I still got ribavirin in the mix. It wasn't a pleasant three months and it wasn't a pleasant time after that. It did play havoc with me, I think. I didn't sleep well. I probably got at best two or three hours sleep a night. I became very agitated, very angry. I sort of tried to keep myself out of the way of other people a lot.

Yes, after the treatment I was that intolerable of other people I went and lived in a caravan in a field with only a cold water type and no electricity for six weeks and I felt great about it. It shows that, yes, I didn't really want -- I didn't like people. I was intolerant of people. It wasn't really like me but it cleared the hep C and that felt great. I had to wait another three months for the all clear, after the three month all clear and, yeah, it felt great.

I'm still left with anxiety from it and a few other, yes, residual issues but not many, but it's great to get rid of the hep C. It really was. It was a massive weight off my shoulders for the basic reason I wasn't infectious any more. It was one less thing to worry about and it gave my liver a better chance of processing HIV meds which I will have to take for the rest of my life.

Q. May I ask you about the impact of everything you have described, the infections, the psychological strain, the treatments on your private and family life and your ability to lead a normal family life. Your phrase in your statement is that you couldn't lead a normal family life.

A. No. No, I couldn't. I think anyone put in the situation, we've all be tested on that one. Because I was so young when I was diagnosed with HIV, yes, my

plans were -- yes, the expression I put in my statement, I had the world at my feet. I expected I'd get married one day. I wanted to have children. I thought being a dad was like a natural progression. It was something I wanted to do.

All that went out the window. I mean, I don't know, finding a partner, having children, all those sort of things, they just fall out the window when you are told you haven't got long to live.

The effect on my parents was huge because they couldn't tell their friends. They couldn't tell anybody. They had to keep it secret. They had a massive range of emotions but, you know, guilt as well because in a way, because they fought for me to have the best treatment available. They read all the information, all saying, you know, about playing the risks down. They thought they were doing the best for me and then I end up with these viruses so, you know, the impact on them was huge.

It's unnatural to lose your children before you and there's a lot of people have given evidence in this inquiry so far that that has been the case and it has been horrific stories to hear. Nobody wants that.

I never thought I'd have a relationship again. My relationship at the time didn't last very long

after my diagnosis. I did meet a woman that became my partner, later became my wife and I felt at the time very, very lucky. I didn't expect -- I just wrote off the idea of having a relationship but we practised safe sex constantly throughout our relationship. We would never have children. It wasn't really an option. It wasn't on offer.

There was a lot of issues around my illness that affected our relationship. My partner, she constantly lived with that, that I might die some time. She joined a self-help group for the partners of those same guys that I was sat with, she was sat with their partners, wives, girlfriends, and as the guys I was sat with died one by one the partners became bereaved partners, so the elements of that group changed from being supportive partners to their haemophilia partners, they were bereaved. Their issues were about bereavement and my partner was the last one in that group that actually had a living partner. So you know she was basically ostracised from that group because she no longer had anything in common with them.

There was a lot of very, very dark times in our relationship but were all based around my illness. When I was very ill before I started my HIV meds that was very hard time for both of us. We both had to

make a lot of decisions. It wasn't a natural relationship, a normal relationship with the normal issues and I always thought I hadn't got long to live. So she always knew that I hadn't got long to live so the emphasis you put on the normal things, arguments or whatever, we changed, you change the way you deal with things. It wasn't natural, a normal relationship.

Q. And that relationship lasted a number of years but then came to an end.

A. Yes, it did.

Q. In terms of the effect of the infections, diagnosis, the treatment, on your education and your employment, your ability to work, how has that been over the years?

A. Well, very sketchy. When I was a child the haemophilia was always going to be an issue. Again, because I said I didn't have factor for many years I just used to have ice packs and bed rest I was off school an awful lot, so the haemophilia played around with my schooling an awful lot. The social services were banging at the door when I had had time off work, truant officer, just to make sure my parents weren't lying about my absences. They tried to get me to go to Lord Mayor Treloars at one point, the special school for boys with haemophilia, as we know. We know how special that was now.

My Mum and Dad, I'm very glad to say brought me up as normal as possible. They didn't want me going to a boarding school. They wanted me have a normal relationship with my brother and sister, to play with the kids on the street, to go to the school down the road and they fought very hard for that, even though there was a lot of pressure.

I'm going of the viruses now. This is just a haemophilia story but, you know, I went to a special school for fairly disabled children. I very rarely had any time off school there. I was very well looked after. I was picked up in a minibus. I actually remember quite enjoying it there in many ways.

I went from my primary school at the time, I wasn't allowed to do sports, I wasn't allowed to play in the playground, I wasn't allowing to go on any trips. Like a lot of people with haemophilia, schooling was quite limited. Then when I went to special school I ended up being the fittest kid in the whole school so I had a complete role reversal. I went, you know, if -- if you were playing football and you were picking teams I was always the last one on the wall to be picked. I went to this school I was

the captain. It was, you know, things had changed.

But the headmaster got quite concerned because I wasn't learning anything. It was obvious, he said, I'd got a certain degree of intelligence. The school might have been good for my health but it wasn't good for my intelligence. I was getting up to 11 then and there was a lot of pressure and, again, you know, my Mum and Dad put a lot of work into that. They got me into the local secondary school, comprehensive, and, yeah, they took me on, even though I still had a lot of time off. I still wasn't allowed to go on field trips, play sports.

Bizarrely, they wouldn't let me do woodwork or metalwork but they let me do catering. For some reason sharp knives weren't a problem as much the other tools were. There were some strange decisions taken about me that didn't -- I wasn't included in the decisions but I just went along with things.

But with the viruses the HIV, I worked in a bank, I stuck that for I think a year and a half/two years after my diagnosis. It was all part of my pretending everything was okay, trying to put a face on things. Let's be normal. I thought if packed in my job everyone's going to wonder why I packed in my job and everyone's going to put two and two together.

So I came up with a plan, if I packed in my job I had to do something else. I went back to polytechnic as it was at the time -- well, went back to, it was my first time I'd been to -- I did a four-year teaching course. I chose that course because it was four years. I didn't think I would see the end of it and I thought it would give me an opportunity to have an excuse to be doing something constructive but also to give me two or three months off every summer to go and see a bit of the world.

I was still alive after the course so I had a sort of natural progression to go into teaching. The career didn't last long. The first time I had a bleed, I had a bleed in my knee that wouldn't settle down. It was a bit unusual. It wasn't being controlled by the Factor VIII. I ended up in hospital.

The head came to see me in hospital, uninvited, stood by my bed and asked me when I would be back at work. I told her couldn't tell her, haemophilia didn't work that way, could she explain this to the staff and she was not mentioning haemophilia in her school. She didn't want -- because if people knew I had haemophilia, they'd automatically assume I'd got AIDS because everybody knew that people with

haemophilia had AIDS. She didn't want her school reputation being tarnished. So she just, more or less, told me to get better as quick as I could. Well, I did come out of hospital and I handed my notice in.

Q. You put it this way in your statement, Paul:

"This was in 1994 and those words were from a school headteacher employed by the county council who operated under anti-discrimination procedures. I went home and handed in my notice."

A. Yes, I did. I think people thought I was a bit mad for doing it, but the fact I had had so much time off with my knee, again it's all about these lies and secrets that you have all the time. You know, "Why did you pack in your teaching job? That was really good."

"Oh, because my knee's really playing me up and I really couldn't -- it was too physical for me. It was a bad choice", you know. So, yeah, I always had an answer for things. It wasn't the truth. It was just an answer. It was just -- yeah, I mostly quite liked that job as well but, yeah. So I had a period in and out of work and I did a few different things. But, yes, the HIV had a massive impact on my career opportunities.

Anybody with haemophilia knows they've got some limitations on their career paths. You know, when I worked in the bank initially that was great for me. I got a job for life. It was secure. It was sat down. It was doable for my haemophilia. I just had the HIV. I knew I didn't want to go and work in a bank until I died. I didn't want to be putting a suit on every morning and working for some institution to keep them happy, you know. It changed everything.

Being told you've not got long to live changes the way you think about life.

Q. You have also described in your statement working for a number of years at the Citizens' Advice Bureau.

A. Yes.

Q. You said this:

"I told most of my colleagues there about [your diagnosis of HIV]. It was a supportive atmosphere in many ways but it was never straightforward. The boss was a gay man. He was very supportive of my health issues in the political dimension. The deputy manager told me attitudes have changed and if she was honest she wouldn't have felt comfortable with me and HIV in her office ten years ago. I had to tell her I had had the virus for 20 years at that time", and then you

have added:

"Her husband was a vicar."

So still in the 2000s you were experiencing attitudes of discrimination and stigma?

A. There's still stigma around today. It's just not as severe as it used to be. The only reason I put that in as an analogy was to sort of say the passage of time, people think, oh, it's okay today but I wouldn't -- it was good to hear them being honest. I can't think of a better organisation to work for because the whole point of working for an advice bureau is you are giving people advice, and people that want advice mainly are very needy people. Everybody who working there was very open minded and very supportive. Yes, it was a good place.

Q. Can I ask about your experiences of the Macfarlane Trust.

A. Okay.

Q. You've described a little in your statement it helped a bit but it felt like a begging bowl. What do you recall of the application processes?

A. They were ridiculous, the application processes. They seem to change year on year anyway, depending you would have -- let's say because of their budgets or their funding but if you wanted anything it had to be

for their set of criteria and their criteria would change from year to year, what they thought was, you know ... in the early '90s they were giving lots of money away for, well, not giving it away, but you had to apply for it for things like white goods.

Lots of people had like night sweats so things like bedding, mattresses, washing machines they were fairly common but if you wanted something that wasn't in their guidelines, yeah, it was difficult. But even if you wanted something in their guidelines, just because they knew you were on their books as such, you were registered under the Trust, they knew these were the symptoms of HIV, you still had to get a letter from your doctor or your specialist clinical nurse. You then had to go and get quotes for bedding, quotes for a mattress, quotes -- and it wasn't just one quote. You had to get three quotes.

I mean, they are talking about somebody who is ill having to run around getting loads of quotes, going to the doctors. I'm sure the nurses and the doctors had better things to do, you know, like treat patients rather than be writing letters of support saying, yes, this person does have these illnesses and, yes, they are experiencing these symptoms.

Then when you submitted all the paperwork you

then had to wait for their next board meeting for them to sit round a table and decide whether they were giving it me or not.

Most of the time you never got 100 per cent. They would give you a percentage. It was hard work. It was almost likely they made it as hard as possible. I felt, yeah, it was a begging bowl.

Bank of Mum and Dad were a lot easier and I was fortunate to have that from time to time when things weren't good. But, no, it wasn't -- it felt like you were begging, and because of that I actually felt there was probably more needier people out there that needed the money. That was the way they made it. There always seemed to be -- they always seemed to reiterate about their reserves and how little they had.

Every December they would send you an income and expenditure form you had to complete. You had to send off evidence of what you paid on your council tax, what you paid on your water bills. It just seemed ridiculous to have to do that every year to show how much money you had left at the end of each month so they could assess how much money they would give you.

So, yeah, this was the only charitable money that the Government said they were setting up as *ex* *gratia* support mechanisms. Yes, they were a support mechanism and at times the money from the Macfarlane Trust was very, very helpful, but it wasn't an easy process.

Q. You have told us about the extent to which some form of counselling, support from psychologist, was something you were able to access a number of years after your diagnosis.

What about your parents whose feelings of responsibility and guilt and suffering you have described very eloquently. Were they ever offered any form of emotional support or counselling?

A. No. Nobody was. None of my family. It was like going back to my Hep B days in '77. The whole family went to see the doctor. The whole family were counselled about it. There was nothing, nothing about the HIV, nothing about the hepatitis C. There was no counselling offered.

I suppose if I had made a case for it, it would be another application I would have had to make for the Trust to see if the Trust could, and they probably would have only -- if you did have any counselling it was only normally -- they would give you six sessions. If you want any more you have to make a case to say whether you want any more or not so, no, they were

offered nothing, no help, no psychological help, no support. No.

Q. You've touched in your evidence already on issues of stigma, in particular how they affected you and the life of secrecy that you felt driven to live. You have I think some wider observations you wanted to make about the stigmatisation of the community, of all people who had HIV.

A. Yes, I do because it's been mentioned so many times over the years and it's been mentioned an awful lot during this Inquiry about -- it's very difficult to think, unless people in this room were there in the day and had the viruses, that the stigma was really acute. It was vile. It was horrible, and it was from all -- from everywhere. There was no escape from it it seemed. There was nobody you could trust, your best friends, there was nobody you could trust not to actually tell anybody else or not to have an attitude. It was like self-preservation to keep it quiet.

But to me the stigma was generated by the way we are in society, which is moulded by the media. I know the media are controlled to some degree by the Government and by policies of the day, the newspapers, the television programmes, they mould people's attitudes and it was people's attitudes that I feel

were wrong.

I always saw a common denominator with, well, the press, the tabloids, started off so many stories, gays, drug addicts, haemophiliacs. Any AIDS story they had those three groups in. I didn't see myself as any different from those other two groups. People don't have a choice whether they are gay or not. People don't have a choice whether they have haemophilia or not. Drug users don't choose to be a drug user, to have an addiction to drugs. It's normally because of some trauma in their lives, because of traumatic experiences that aren't picked up by the health, by their GPs, by their doctors. They were self-medicating.

The gay society, because they were seen as the underdogs, it was like a separation from what is normal society and abnormal society.

Having haemophilia, having a disability, you were put into that bracket too. I felt a kinship with the gay guys met and the drug users that I met. That's where I got my support from in the drop-ins and it worked two ways as well because a lot of the drug users and a lot of the gay guys that got to know, they hadn't had the experience that had, a childhood of being able to converse with doctors, going to

hospital, going to clinics, understanding what your blood results meant. They were part and parcel of having haemophilia. To a lot of the others it was the first times they have actually come in front of any clinicians.

So, yeah, I'd be helping them in like questions to ask your doctors. In fact, I did a workshop with a friend of mine who's been involved with this Inquiry for one of the Mainliners' conferences and the workshop we did was getting the most out of your doctor, understanding your test results, how to speak to your doctor, don't be fobbed off, be confident to question them, go on with a list of questions, don't leave that room until you have had all your questions answered, if they are using words you don't understand ask them to explain them.

It was that kind of thing. On that two-way street, those gay guys and drug users with hep C, with HIV or with both, they were giving me experiences about their management of their conditions and what drugs they were taking to help their conditions and their experience of interferon or whatever was going.

I felt those two groups of people were very supportive to me, their support organisations were part of the help that I had. It's the media that's at fault for stigmatisation that all three of us had.

Maybe so many gay guys wouldn't have had HIV if the education was put there and the support network was put there, if they felt comfortable to go to health clinics or doctors, but they weren't. They were stigmatised.

With drug users, rather than blame the drug users, maybe they should have been blaming the health authorities for not recognising this earlier and giving them clean needles, clean syringes, you know, support networks, advice about taking drugs. It would have been a lot more easier than blaming gay guys or blaming drug users for the spread of this infection, blaming haemophiliacs for the spread of infection because people with haemophilia did spread this unknowingly, and we've seen this time and time again during the Inquiry where the doctors have known in some cases for years before they have even told the patients of the diagnosis.

People have infected their partners, their wives. It was all unnecessary. It was unnecessary in the haemophilia population, as it was in the intravenous drug-taking population, and the gay population.

One thing that cemented all of this, as an

example which we talked about, in the -- I think it was about '87/88 or probably might have been even earlier, I don't know, when you are brought up in life you see institutions that are there for you, the Government, the police force, the church, whatever, they are the establishments of our society.

James Anderton was a guy that was a public figure, who was the Chief Police Inspector of Greater Manchester Police. He stating in the press and in a BBC religious programme -- he used the quote, "people with AIDS are swirling in a cesspool of their own making". That was a horrible thing to say. I don't know whether he was referring to people with haemophilia then but to me it didn't matter who he was referring to. He was referring to people with AIDS who were swirling in their own cesspool of their own making.

We've got a senior policeman, who is also a Christian, it was on a religious radio programme I think or a religious TV programme this came out on. To me I've got the police and the church both in hands, both saying that this is a product of our own making, we created this. It is like negating the responsibility from the Government, from the Department of Health, from the people that were

responsible.

Margaret Thatcher a few years later knighted James Anderton. He became Sir James Anderton. So then politics comes into this again. The guy that said these things actually gets rewarded by the Prime Minister.

For somebody living with HIV at the time, this is someone who was just increasing this stigma and it's not someone that's a man in the street, it's not somebody that's ill-educated. So, yeah, those establishments that are there, that we are supposed -- that we are brought up to look up to had -- I had lost my faith in so many institutions, at the same time increasing my anger towards these institutions at the same time.

Q. Paul, those are the questions I have for you. Before ask you if there's anything you want to add, I am going to turn and ask Ms Monaghan if there's anything further she would like me to ask you.

A. Thank you.

MS RICHARDS: Paul, there aren't specific questions but Ms Monaghan has reminded me perhaps to remind you that you, I think, in your closing observations may want to say something about pharmaceutical companies. But there are no further specific questions from me. If

there's anything further you would like to add, this is your opportunity to do so.

A. Yes, I just hope this Inquiry -- I do realise most of the pharmaceutical companies involved in the infections are American. I can't -- because of a legal case that happened in the States, I -- it's very difficult, I think (my own observations), to bring those to book or to account or to actually have representatives of those pharmaceuticals sat in this chair next year.

But what I would like to look at is the relationship the Government, the Department of Health, and the doctors had with those pharmaceutical companies because if this Inquiry is going to change anything in the future, we've got to be looking at the relationship with the pharmaceuticals. Even going back to that press clipping where we started off today's talk of 1975, the Department of Health (or the DSS, as it was called) had set up contracts with two companies and it mentioned them as Travenol and Speywood products. It then goes on to say that the Department of Health was now setting up contracts with two other companies. It didn't say who.

The questions I'd like to know was when they have -- when the Department of Health or the

Government have contracts with pharmaceuticals, what measures are taken regarding safety of products? Has actually -- because we've never had an inquiry into what happened to us, how do we know that things have actually changed? Is it profit-driven? Is it just about budget? Is it about safety? Trial data: do our governments or Department of Health scrutinise the trial data of the drug companies, the pharmaceuticals say are the reasons for their use?

I just would like some more robust -- to give confidence not just to the haemophilia population, not just to the other people that have been at this Inquiry that have been infected with hep C through blood transfusions, but to everybody, every citizen, not just of this country, probably the world. When pharmaceuticals are such multi-billion businesses now, the law firms of pharmaceuticals, the law arms, are huge themselves. There's a reason for that it's because they're constantly defending actions against which they've have gone wrong. We've seen it with all sorts of different -- thalidomide, for reasons -- all sorts of illnesses and diseases, they're all in the -- going on. There doesn't seem to be an end to it.

I just would like to see pharmaceuticals not get away with what they've got away with in the past and

I know a lot of people with long-term medical conditions wouldn't be living without those medicines, and I still wouldn't be alive today if it wasn't for the pharmaceutical companies that make such very good HIV drugs. I managed to clear my hep C. I'm not saying that they're the enemy but it's the way they do their business which is wrong -- very, very wrong.

Q. Is there anything else would like to say, Paul?

A. I'll probably think of something in half an hour or an hour, but I think I've held people's attention for enough and, yes, I think we'll -- I think I've said enough.

Q. Thank you. Sir.

A. I would like to thank you Sir Brian for bringing this Inquiry. Yes, I'd like to say that anger you talked about, that anger that brewed inside me, that went out the window the day this Inquiry was announced because I felt very seriously for once that something was being done about it. I've got full faith in this inquiry. So thank you very much.

SIR BRIAN LANGSTAFF: For my part, I think I might very much have enjoyed being a pupil in one of your classes when you were briefly a teacher. You put matters over so engaging and persuasively. Thank you very much for that.

A. Okay, thank you.

SIR BRIAN LANGSTAFF: We'll take a break now and it will be a lunch break, slightly earlier lunch break than usual, and we will come back at 1.05.

(12.10 pm)

(Luncheon Adjournment)

(1.13 pm)

MS RICHARDS: We can now hear you I think in there. Can you hear me?

A. I can hear you.

MS RICHARDS: We're going to start, Mr AH, with Sir Brian making a restriction order.

SIR BRIAN LANGSTAFF: I don't know if you can see me or not but you will hear me speaking. Can you hear me?

A. I can hear you speaking, yes.

SIR BRIAN LANGSTAFF: As you can understand, I was going to say see but you can't, as you can understand this witness is not in the room. He is witness W1006. In his case, I make the following order. The name and address of witness W1006 (that's Mr AH to you and me, that's how he will be known), the name of any member of the witness's family and any other identifying information such as the witness's image or a description of their appearance or, in this case, the sound of his voice cannot be disclosed or

published in any form unless express permission given by me or by the solicitor to the Inquiry acting on my behalf.

Witness W1006 must be referred to only as Mr AH. This order remains in force for the duration of the Inquiry and at all times thereafter unless otherwise ordered and may vary or revoke the order by making a further order during the course of the Inquiry.

MS RICHARDS: Mr AH, I think you are now going to be asked to swear the oath or affirmation.

MR AH, affirmed

(Evidence given via audio link)

Questioned by MS RICHARDS

Q. Mr AH, you have severe haemophilia A which was diagnosed when you were a baby.

A. That's correct.

Q. From the age of one in the late 1970s you were treated with Factor VIII for your bleeds.

A. That's correct, yes.

Q. During this time you were under the care of Lewisham Hospital and you would receive Factor VIII fairly frequently, perhaps, as often as every couple of weeks?

A. That's true, yes.

Q. In terms of the product that you received, we've got a printout from the UKHCDO database and that shows that in the period from 1978 through to the mid-1980s you received occasionally the NHS BPL Factor VIII but rather more frequently you received a variety of different commercial products, pretty much all the products that were available at the time you as a baby and young child received?

A. Mm-hm.

Q. As far as you know, were your parents told anything, given any warnings or information about any risks of infection associated with the products?

A. No, none at all. They were never informed of any risk.

Q. It was in 1984 or thereabouts when you were seven or so years old that your parents were given some information about your diagnosis. What were they told?

A. So it would have been my mother, my mother always attended appointments with me or for me and she was told that I had tested positive for the HIV virus and that they should enjoy me and my life as much as they could and prepare for me to die within five years.

Q. Were they given any other information at the time about the virus or any practical steps that should or could be taken to manage it?

A. I do believe they were told that it was a difficult virus to catch and to treat me the same as any other boy.

Q. You weren't told that at the time, given your young age.

A. No.

Q. But you have described in your statement how even before you were told, the atmosphere at home and family relationships changed. What can you recall about that?

A. Yes, it changed very much so. I remember the household being happy. Mum and Dad laughing and joking and listening to music a lot, dancing and then after my diagnosis the household became quiet. Communication was strained. My Dad became introverted and there was -- I mean, there was a lot of stress.

As a young child and my sister being young at the same time we could feel it, we could feel just the stress and it's almost like we knew there was something wrong, even at that early age.

Q. It was about five years before you learnt, when you were 12 years old, that you were HIV positive. How did you learn that information?

A. So I had been admitted to hospital with an HIV related illness. At that time I don't know I was positive.

I developed a severe cold and chest infection. We were on our summer holidays and I just felt this was strange to be this ill in the summer. Usually it's in the winter we get coughs and colds, don't we. It all seemed very odd to me and it was worse than any other cough or cold I had ever had. I was very disoriented, high temperatures and feeling terrible, so I was then admitted to hospital, given antibiotics and, yes, at this stage I still didn't know why I was there or what was wrong with me.

Sorry, did you ask how became aware?

Q. Yes, how you learnt this news?

A. So I think it was probably on my second admission to the hospital, because from this point onwards I was frequently admitted and I was one of the older -- so I was around 11 or 12 years of age and I was in a child ward. There was a play specialist that was there for the children and a teacher and, kind of, developed a relationship with this play specialist and she took a shine to me. She seemed to be very sympathetic towards me more than the other children there.

She took me out one day, she had an errand to run, it was internal mail for the hospital and she said, "Would you like to come along with me". I would

take any opportunity to get off the ward so I said, "Yes, of course", and we wondered around the hospital, delivery ring and then I could tell from her she was uneasy about something and at this time I realise she was plucking up the courage to tell me I was HIV positive.

She took me outside, we had a chat, and she said to me, "you are" -- she told me I was HIV positive and that -- I mean, I didn't really know what that meant at the time but she said you've got to be very careful when you are around girls, if you cut yourself. That's basically what -- that was the reason why I kept becoming ill.

I found this shocking because surely if anyone should tell me it should be my parents or a doctor and from that time onward I became very introverted. She took me back to the ward and just sat on my bed and I didn't know what to think. I was shocked and disturbed. I was 12 years old. I couldn't process that information correctly.

Q. You have said in your statement you saw her one more time before she left. She was asked to leave the hospital at a later stage when the nurses found out about this.

A. That's right.

Q. You asked her why she decided to tell you you were HIV positive and what was her response?

A. So obviously the nurses and the doctors found out very quickly what she had done and what she had said. She was asked to leave. I saw her one more time and I asked her, "Why did you tell me this? Why did you say this to me", and she replied with -- said, "I thought it was very unfair that you didn't know", and I very soon found out that when I was put into the ward my parents said, "We don't want him to know *(unclear: interference)* young. We'd like to do that ourselves, we'd like to tell him ourselves", so in effect she just -- this play specialist felt that was unfair. That wasn't her judgment to make. I had built up a very good friendship with her so I didn't blame her at the time for this, but thinking about it later on, you know, she had no place to do what she did.

Q. You have described in your statement that this was the time when you began having psychological difficulties. You had been given --

A. Exactly, yes.

Q. -- this information in this way. You felt confused and lonely and it was the beginning of a very confusing time?

A. Yes. I definitely started to develop psychological difficulties and I felt scared, lost and I couldn't -- as I said, I couldn't process the information. I was very confused why would this happen to me? It was, yes, an extremely difficult time, yes.

Q. What was the effect, after you had learnt your diagnosis, what was the effect of that on life home and your relationship with your parents once you knew that this information had been not previously provided to you and they knew that you knew?

A. Well, my parents explained why they didn't tell me straight away. I felt angry because, you know, I was 12 years old thinking, you know, "I'm nearly a teenage, why didn't you tell me these things". At a later stage I completely understood why they didn't tell me while I was that young.

I was angry. I became introverted. I'd stay in my room. Communication between my parents and I just became even more difficult and I felt that I had to protect them. I felt knew they were upset by this. I knew it was incredibly difficult for them, so I -- I literally took it all on myself, you know, that I was causing people to be hurt and I wanted to protect my parents. So I just -- I didn't talk about it. I wouldn't talk about it and I stayed away from them as much as I could.

Q. You also learnt at a relatively young age that you had been infected with hepatitis C. How did you find out about that?

A. Yes, so that was around -- no, between '89 and '90 I was back on the ward and in hospital with an HIV-related illness and I was in a bigger bay this time. I wasn't in a room on my own I was in a bay with other beds but there were no other children in these beds.

A nurse came in to see me and she just flippantly said, "You have been tested positively for the hep C virus". I didn't know what that was so she briefly explained it to me. She said, "This won't become a problem for around *(unclear: interference)* years so it's nothing much for you to worry about. Kind of, for me it was indicating that, you know, HIV/AIDS would kill first so it wouldn't matter and then (interference) my parents hadn't been called in to hear this is information with me. No-one was with. She just gave me the information and walked away.

Q. It was I think some time after that that your parents decided to take you to see a specialist at Saint Mary's Hospital and in the period that followed you said in your statement you found your new clinicians more helpful and forthcoming in terms of the information that you were provided with?

A. Exactly. They took me out of Lewisham Hospital to Saint Mary's in London where there was a specialist HIV doctor. I was treated so much better there. They had a lot more information about the virus and the HIV-related illnesses. I felt -- well, I felt awful. I had full-blown AIDS by this point and I felt terrible.

I didn't really want to make the change of hospitals because I was so happy with Lewisham. I had been there all my life but *(unclear: interference)* I felt this ... so much more educated on this virus and what it did to me. It was at this point that obviously I felt terrible, every night I went to sleep to die. I wanted to die in my sleep -- it wasn't until I woke up each morning as that feeling of just hurting everyone around me and causing stress, it was just too much to bear and I felt so terrible. I really just wanted to die.

Q. Because it was in your early teens that your HIV diagnosis was progressing into AIDS and you were physically very unwell as well as having to deal with the emotional psychological and mental impact of the diagnoses.

A. Exactly. It was a hell of a lot for a young boy or young teenager to deal with. It was impossible. I couldn't deal with it. I just did the best I could. I've always said I did the business with the cards that I'd been dealt with in life. I just wanted to try my best and survive.

Q. You have described in your statement the profound psychological impact of the diagnoses, the infections. You became very depressed, introverted and later suicidal, and you didn't have anyone you felt you could talk to.

We've heard from other witnesses about the stigma of HIV and AIDS in the 1980s and 1990s and how it affected them. Can you tell us how that affected you?

A. So I suppose it started with the media and the adverts on TV, the scare mongering and as haemophilia and HIV became more widely spoken of and linked there was an occasion where my mother was called into school to see the headmaster and he outrightly asked her, "Has *[redacted]* got AIDS?" My mother felt forced to cover up the truth. She just wanted me to be treated as a normal boy and *(unclear: interference)* and not be kicked out of school and ostracised that way.

So I don't think the headmaster ever believed

her because of the feelings I got from the teachers and the supervisors, after that everyone just looked out me with disgust. I just felt they were all talking about me behind might back, so that was my first stigma that ever affected me.

Also, at a later date my Mum told me when she went to pick me up from school the parents wouldn't talk to her. No-one would talk to her, you know. As said haemophilia and HIV was linked with the news. It was all over the papers and that's when the stigma began for me.

Later on, I was in my local swimming pool and one of the lifeguards -- I said I had haemophilia to one of the life guards and she asked me if I was an AIDS kid and I didn't understand what she was talking about at all.

I went to my nurse at the time and I said, "What's an AIDS kid", and it wasn't until many years later when I was in my 20s that she said to me, "I remember when you said that to me and I didn't know what to say to you". Of course, she didn't answer the question but it became -- I became aware that if you talk about haemophilia then people begin to link AIDS and HIV, hep C to that.

Q. Although times have changed, you still are conscious

of the stigma, in particular in relation to your own family nowadays?

A. Mm-hm, yes. That's why I'm anonymous. I want to be an anonymous witness now. I don't want my daughter to suffer from stigma the way I did. My wife kind of lives a double life where she doesn't speak about -- it's hard to speak about me and my illnesses when she was at her place of work in case started people to link things together again. I believe a lot has changed in the way of stigma but just not enough, not enough. Our main priority now to protect our daughter from any kind of stigma, especially in school and in fact my wife's mental health has been severely affected by this and on top of all of the illnesses I have had as well recently.

Q. In your teens you had been prescribed opiate pain killers in hospital. Can you tell us about what followed from that?

A. So there two things that follow from that. I was given opiates from a young age. Being a haemophiliac I was in a lot of pain but also with illnesses I was also in a lot of pain, and so I began to self-medicate with opiate painkillers, not really understanding what I was doing but realising that when took these pills they made me feel better, that I cared less about

what -- my difficulties in life and I began to increase the amount of painkillers I took every time until I was taking handfuls of opiates and then when I finally told someone, it was a nurse that was made aware, you know, that I was -- it was risk-taking behaviour. I was taking overdoses every time. I would just take an overdose of opiates and then just fall asleep on the sofa and feel better.

But there's a bigger implication of my opiate use but the opiates I was given in hospital I was -- every time I was admitted I was given pethidine basically and as haemophiliacs can't have intramuscular injections I always had it IV, so basically I became addicted to opiates every time I went into hospital.

On one occasion there was a doctor that came to me early in the morning, must have been about 3 am, I complained of being in pain again, needing more pain control, and he came to my room and he asked me if I liked pethidine and I was young. I felt ashamed to tell the truth but I said, "Yes. Yes, I do". He said to me, "Do you like the feeling it gives you when it's pushed into your vein", and, again, I said -- again, I was very shy and kind of ashamed to answer these questions but I said, tentatively said, "Yes. Yes, I do". He said, "Do you like the rush it gives you through your body". Again, I said -- and at this stage I really felt awkward but I said, "Yes, I do", and he then proceeded to push it into my vein extremely fast, when other nurses or health -- nurses or doctors when they give it, they give it over a time period so that -- they give it slowly and over a time period so that you don't get that shot of euphoric feelings. He just pushed it into my arm very, very fast and I felt -- I won't lie, I felt very good but just euphoria filled my body, but I realised this was wrong.

The protocol after giving someone a shot of pethidine is to sit with them just in case there are any adverse effects. There is guy just left my room. He just left me on my own.

Q. You transitioned, as you put it in your statement, from using legal drugs to self-medicate to becoming embroiled in illegal drugs which you would use because of your addiction?

A. Yes, and just escape my every day life that I just couldn't handle. I would have done anything. You know, I even thought of suicide just to escape how awful I felt. It was so difficult when I was younger.

Q. You put it in your statement this way: it was your way

of escaping the mental torment you were experiencing --

A. Exactly.

Q. -- of every night going to sleep wanting to die and being disappointed when you woke up each morning.

A. Very much so.

Q. How physically has your health continued to be over the years? You have experienced lots of illnesses and infections and suffered the effects of the anti-retroviral medication. What can you tell us about that?

A. Sorry, could you repeat that question, please.

Q. Sorry, it was a long question. I'll break it down.

You have experienced many infections over the years as a result of your HIV. What could you tell us about that?

A. So it all started with pneumonia, bouts of pneumonia, numerous each year, and then later on as I got worse, as my CD4 count literally dropped to zero, I had PCP, it's a type of pneumonia. Then the PCP spread to my kidneys and the doctors had told my parents they had not seen this much before if ever and they didn't know what to do with me. Basically, my parents were told I was going to die.

I think they gave me every drug they could to

save me and that was probably one of the -- as a youngster, as a young teenager the worst times for me, the worst illness I had. I had a kidney biopsy so they could find out what was wrong, which went wrong. When they were giving the biopsy they put the needle through a major artery and I bled profusely for days, just complicating matters even more.

On top of the pneumonia and the kidney problems, I had horrible constant stomach pains, headaches. I was tested for brain cancer or are a tumour on my brain, which came back negative.

These were the illnesses I had in my younger years. The other, what would call minor stuff, would have been incredibly itchy skin, lesions all over my legs and my arms that I would just scratch off. I would scratch everything off and then just bleed and need to be bandaged up but the strange thing was felled cleansed by this. If I scratched all these lesions off I felt as though I was cleansing myself from the virus or the illness. That was the way my mind was working.

In fact, what I was doing was just causing myself to bleed a hell of a lot and causing more infections by doing that. My doctor spoke to me once and said my CD4 count was zero for seven years. I

literally had no immune system for seven years and he had never seen that before in a patient.

Q. You were given AZT. What happened?

A. I was given AZT from the age of 12, so shortly after my first bouts of pneumonia. As you probably heard from other witnesses, at that time it was a very new drug and they didn't know what kind of dosages to give to children or even adults. They just didn't know. So they later on I found I was taking -- they were giving me more of an adult dose of AZT which had terrible effects of my body, vomiting every morning, diarrhoea. It would knock my red blood cell count so I was anaemic many, many times and I had to go into hospital for blood transfusions for that just to top me up. Again, my red blood cell count would just get knocked down again.

I literally couldn't leave the house for hours and hours in the morning because I had the most terrible diarrhoea. Whatever medication they used to stop it just really didn't work. It was a terrible drug to give. Constant headaches? Stomach pains. Yes, it was -- it was meant to be helpful to slow the virus down but I believe, as some other people have said, it just made us worse and up to today I don't think it really helped much at all.

Q. In 2007 you underwent treatment for hepatitis C with interferon and ribavirin for 12 months. What was that treatment like and what was its effect on you?

A. Yes, I did 12 months of interferon and ribavirin and it just changed me, overnight it changed me. I wasn't the person that I was previous to taking these drugs. I became incredibly angry. I had violent outbursts. Again, it made me anaemic. I was very, very weak. My now wife, who was my partner then, just felt like she was living with a stranger. She didn't know who I was. I did not know who I was. My wife had to go part-time on her job to look after me.

Also at the time my sister-in-law was living with us and I just felt like I scared her all the time. I mean, I was an angry, angry person and I believe I did scare her. I turned into a monster, basically. I was quite psychotic to tell you the truth. It was an awful, awful time.

I believe that was the time that I started to develop PTSD type symptoms, so post traumatic stress.

Q. You clearly --

A. And even after the treatment I felt incredibly anxious and it's left the after effects -- I've still got things with me now that -- you know, mental health difficulties due to that treatment.

Q. The hepatitis C virus cleared from the treatment but, amongst other things, you continue to experience what you described in your statement as intrusive flashbacks to that time.

A. Absolutely, yes. So I actually cleared the virus in three months. I remember my hep C doctor bouncing up and down in his chair he was so happy but I couldn't care less because I felt extremely ill and possibly suicidal at the time. He was very happy but I had to carry on doing 12 months of this treatment and then after that I started to develop these intrusive images.

It was what these images were of myself being attacked from behind. It was always that I was being attacked and I could see this -- I could see it in my head, I'd been walking. It used to happen when walked down the road to a shop and it was almost that I could visualise someone coming up behind me and stabbing me in my back, my lower back to be precise, very strange, so I would feel quite vulnerable. I looked over my shoulder a lot. Very, very strange and -- very strange.

I've discussed this with a psychologist and, you know, I've never been attacked like that. I've never been hurt like that. It's very strange, very strange.

Again, you know, the vulnerability that that causes is disturbing, very disturbing.

Q. Had you previously at any time been offered psychological support or counselling during your teens and young adulthood?

A. Yes, in my teens I was -- well, probably earlier than that, I was sent to a child psychologist and I just sat there quiet. I didn't answer this guy's questions. I didn't want to be there and being a trained *[redacted]* now, and looking back at those times he didn't know what to do with me. He didn't know what to say and, in fact, after that I've had counselling and -- since, and a lot of the time in my teenage years it's very, very clear to me now that they just didn't know what to say to me so I never received any helpful counselling, any helpful or structured ways to get over the issues that I had.

Q. In 2012 you were diagnosed with chronic kidney disease and that led ultimately to a kidney transplant in 2016. Can you tell us about that.

A. Yes. So my kidneys were declining and I, as we all have, we have appointments with the HIV doctor and blood tests would show that my kidneys were declining. This was made clear to me and I was told to drink more water, simply just drink more water, until it got to the stage where I was sent to a renal specialist, and went to see a doctor at Guy's Hospital and he just bluntly came out with the fact that I needed a kidney transplant. There was nothing they could do and that I needed a kidney transplant and I couldn't believe what he was saying to me. I had to ask him to repeat what he had said, you know, and it became clear. I processed the information he was giving me, but I couldn't -- I thought at this stage in -- I cannot remember the year now when he told me but I thought all the illness was -- had -- it was over, you know. I'd come through being a teenager, to a young man, suffered a hell of a lot, had so many illnesses and problems that I thought, yeah, this is over now. I can live my life. Then I find out I need a kidney transplant.

Then before went to see the renal doctor, I was given no indication by anybody else, any other specialist doctor, that I could probably -- I had to expect that I would need a transplant. It knocked me for six. I didn't know what to do.

Q. You have given a lot of thought to what caused your kidneys to fail and your belief and understanding is that it can be traced back ultimately to the hepatitis C infection?

A. Yes, there is once I started to do a bit of research or mostly my wife was doing the research, we managed to talk to a professor, a renal professor, at Guys because the not knowing what had caused the deterioration in my kidneys was horrible. It was again I was mentally tormented by this. I think the not knowing is sometimes the worst part. So we saw this professor and we said could my renal failure be linked to hepatitis C in any way, even though I had cleared the virus by now on treatment.

He said, well, yes, absolutely, completely. We were shocked. We didn't expect, you know, an answer that like, the fact that he would be so sure that it could have been hep C, and I reminded him, I said to him but I've had treatment and I never had a high viral load for hepatitis C so it never became very destructive for me. And he said, no, no, it wouldn't have been. It can be the underlying effects of hep C just like what you would call a grumbling appendix, a grumbling element to hep C. It can cause kidney failure. So I was shocked by that, happy that I'd cleared the hep C virus years before but then thinking, well, I may not have got away with it all, you know. It could have damaged me like this and, again, I say could have but it seemed quite clear to

this guy that that's what would have contributed to my renal failure.

Q. Earlier this year you had to have major heart surgery. Could you tell us about that.

A. Yes. I began to feel -- to have angina which I -- I was in denial. When I felt these pains in my chest I was in denial. I had -- as I've had most of my life difficulties with my mental health I thought I was having panic attacks and that's why my chest were hurting.

So I -- I kind of denied the fact that I could have my heart issue. Actually, in effect, these angina attacks only came on when I was injecting the clotting factor so initially I thought I might be having a reaction to the clotting factor I was given, not that I'd ever had one before. I'd asked nurses what it would feel like if had a reaction and I was told you would definitely know about it, nothing more than that.

So when I was on prophylactic treatment, using treatment every other day, when I was infusing it I would get pains in my chest and I thought this isn't right, it's strange, it happened once or twice and then it started to happen every time gave myself an injection of factor clotting products.

I was worried by it but I didn't want to admit to myself that there may be something else wrong with me so I went, I don't know, maybe a year doing this, just living in denial and telling myself, you know, there's nothing wrong with my heart until started to get angina. I had angina just on simple exercise or walking fast I would feel something wrong.

So then I -- the next thing that happened was I was giving myself a shot of clotting factor late at night, I was in bed, I think about 10 or 11 o'clock and I injected this factor. When it finished I got -- I felt really, cold sweats, pains in my chest, a pain along the left side of my jaw, couldn't breathe properly, I felt absolutely awful and I thought -- I didn't really panic but I thought this is really bad. There's something wrong with my heart.

I didn't wake up my wife. I just -- all my life there had been a lot of panic around me and people rushing around and I just -- I didn't want any of that. So I should have called an ambulance but I just fell asleep and I then found out later I was lucky I woke up in the morning.

The next morning I did wake up. I went to my local Haemophilia Centre, they took some blood tests, one called a Trop-T test, which measures enzymes in

the blood that can be created when you have had a heart event as they call it. This drop-T result came back as elevated and I asked the doctor what does that mean, and he says it indicates that you could have had an event. I said what sort of event? What you talking about? He said a heart attack.

So then thought, "Oh my God, you know, now I've got something else to contend with". The thing was ever since I had had the kidney transplant I couldn't recover. I couldn't retrieve any kind of stamina after the kidney op. I was very weak. I couldn't really understand this but it seems that I had had my arteries, my heart arteries, had been damaged. I later found out they had been damaged for years. This had been an ongoing thing, my arteries were shrinking. They were extremely thin in some areas and then they were aneurysmic, so they were very swollen in other areas.

This was after it was all diagnosed and I was in hospital being tested I found this out about my heart arteries.

Q. You had a triple heart bypass operation.

A. I had a quadruple heart bypass operation. That won't be in my statement because when I wrote my statement they told me triple. They didn't want to open me up, obviously they thought I would have a lot of problems with bleeding so they tried to control my condition with medication and they were giving me very high doses of medication which weren't working. I was still having angina, so I went back to the cardio clinic and spoke to a doctor and I said, "Look, I'm not getting any better", or the symptoms aren't going away. He then said to us, to me and my wife, "Do you want to have a look at" -- had some scans done. He said, "Do you want to look at the scans", and stupidly -- I'm always interested so said yes and he showed me on the screen my heart and the arteries around it and they looked terrible. They looked awful. I couldn't believe looking at.

As I say, they were what they call -- I had lesions and aneurysms in the four major arteries of my heart. My LAD -- and I am not sure what that abbreviates to but it's also nicknamed the widow maker artery. That was blocked, 98 per cent blocked, so the only thing that was keeping me alive was the fact that my heart, my clever heart, had done its own bypass in a way. It has used other veins and smaller arteries to bypass these blocked ones to give me enough to push the blood around my body enough to keep me alive. But still I had angina to alert me to this problem.

Q. When you --

A. Go on.

Q. Sorry, Mr AH. You've been told by your doctors that the heart problems that you have described are, in large part at least, due to the immense strain on your heart through the HIV infection and illnesses and the treatment you have received for HIV?

A. Mm-hm. Yes, some of the drugs that I've taken over the years haven't been good for the heart. My actual heart is fine. The function of my heart is good but the arteries were destroyed. I had an arterial disease that has been attributed to some of the medication I was taking, some of the HIV drugs.

Q. In your statement you say this about the impact of your infections:

"The impact of HIV and hepatitis C infection upon my life has been all encompassing since I would have been infected from the age of 1 year old. I didn't have the chance to experience life without these viruses. What would my life have been like without HIV and hepatitis C? This is a question which has affected my mental health considerably over the years so I came to the conclusion that I must do my best with the hand that I have been dealt."

A. Absolutely. Like said earlier, the not knowing is

possible the worst thing. I have strived really hard to live as normal a life as I can and now, you know, I've been lucky to -- I met a partner. Now I'm married. We have a daughter. That's a very large amount of my life I feel that I have some normality but in earlier years not at all.

Even right back to childhood my family was affected by all of my illnesses. My sister felt that she was neglected because my parents just focused all attention on me when I was ill, and I was ill all the time. It caused all sorts of difficulties at home. You know, I love my sister very much and I'm upset that she felt left out. That's a common thing, you know. It is a common thing. But just everything about my life has been different because of these viruses. I don't even know how my life could have been different. I'm hoping it would have been a lot better and I can imagine it would have. Again, yeah, all encompassing. I don't know who I am and what I am.

A lot of me is a product of having these two viruses and everything else that has been any kind of normality for me I've had to really fight for. I have had to fight so hard to feel like a normal person.

Q. What's the impact of everything you have described

been upon your parents?

A. The impact upon my parents, yes. As I said earlier, my mother mostly looked after my health issues, appointments, and also when I was being treated at home for my bleeds it was mostly my Mum that was giving me injections. She had a huge battle with herself later on in life because she felt she'd given me the infected doses of Factor VIII, and that's just -- that's still with her today. You know, she hasn't bounced back from that and I don't think she will unless I could find out which batches of factor actually infected me. My Mum had a breakdown. My mother and my Dad became distant. Later on they divorced.

You know, I felt -- not because of my mother and father's break up but I just felt scared and lost for most of the time. My sister felt neglected. The whole household was affected by this and I'm sure you know that's an ongoing theme for a lot of people but, you know, somebody I feel needs to answer or there need to be some answers for any kind of healing to occur for myself and other people in my community. I believe it would help a hell of a lot.

Q. Your wife, you've touched on the impact upon your wife of looking after you, and all the very substantial physical health problems that you have experienced over the last few years. What's the ongoing impact for your wife and your daughter?

A. Okay, so we try and -- well, we try and shield our daughter as much as we can. It was difficult when I was in hospital for my quadruple bypass because there are a lot of difficulties. I bled huge, huge amounts. I was in critical care for a long time and I had to be opened three times for them to clear out all the blood in my body.

My daughter didn't know where I was. Obviously, she's *[redacted]* now and we couldn't tell her where I was, so she had to live without her Dad for these 38 days that I was in hospital.

My wife has basically -- she's my carer. She's -- when I can't research some of these illnesses, she's doing research for me or for us. My wife has had to put her career on hold. We just live off of my finances. It's -- especially the last five years have been incredibly hard. I've got one kidney now that that could last 15 to 20 years if I'm lucky and then I'll need another one. I've had my arteries replaced with a vein from my leg and hopefully they will last 10 to 15 years and then they will need further work.

You know, it's never over. It's never going to be over now and at one stage in my life I thought it was going to be over. I'd make plans for myself and my wife, plans that we couldn't fulfil or it would be incredibly hard to fulfil.

You know, the impact of having two viruses is just -- I want to say destroyed my life but it's not destroyed me. I'm a survivor. I'm not the victim. I'm a survivor and I will do my best with what I've got, as I've already said. Just things keep coming up and I'm basically scared. I'm scared for my future. I feel like a ticking time bomb especially with the kidney. In my lifetime I will need another kidney. in my lifetime I will need my heart arteries worked on again and that creates a hell of a lot of anxiety, post traumatic stress.

So although things got better at one stage when we got new anti-retrovirals, better haemophilia treatment, it's not over for me and it never will be. That's the way I feel, and more than that, not over for my family, my daughter is *[redacted]* years old.

Q. Your education was very significantly disrupted because of your illnesses but a few years ago you decided you wanted to use your skills in a positive way and you undertook voluntary work but you have not

been able to earn a living from it. You describe yourself in your statement as having to live on what you term as handouts from the *ex gratia* support schemes?

A. That's right.

Q. Why don't you tell us what your experience has been of those schemes, the Macfarlane Trust, et cetera, and latterly the EIBSS.

A. So if talk about the Trust or the English Infected Blood Support Scheme. The other day I was talking about the money we receive from them and I was referring to them as payments and realised what I was saying when said the word "payment". You know, I'm not doing a job. This isn't a payment. I'm not being paid for anything. What am being paid for? The wording just felt ridiculous. It felt ridiculous and -- I can't think of the right word, incompetent? Incomplete?

With regard to using the schemes I had heard about how difficult it had been, from early years I had heard about how difficult it had been to apply for grants and I decided I didn't want to have to feel like that. So I wouldn't apply for grants and I didn't -- I was tired. I didn't want to fill out forms. I didn't want to answer intrusive questions.

I didn't want to have to justify what I needed in the form of answering a bunch of questions about, basically, my -- I was going to say personal income but income even sounds terrible to me, but the way in which I used the money that they supply me with, I don't want to answer those questions. It feels demoralising, so ...

The scheme changed from the Macfarlane Trust to the England Infected Blood Support Scheme, which I think is a disgusting name and nothing really changed. You know, not much changed. You talk to them on the phone and they don't even know what you're asking them.

They don't understand -- I believe that the training they have been given is inadequate, the people that answer the phones, the phone operators. There are a few people you can talk to that actually understand or realise what you may need. I just try to stay away from them as much as I can.

Q. Those are the questions I have for you but I am just going to move away from the screen and ask Ms Monaghan, who represents you, if there's anything further she would like me to ask you.

A. Mm-hm. Thank you.

Q. There are two points that Ms Monaghan asks me to raise with you. One is about the uncertainty over the potential long-term implications of the drugs that you have been receiving over the years. You are the generation that has been through these various drugs and I think you wanted to say something about that.

A. Yes. In effect, we are -- the people that are surviving today, we're the longest standing community of people that have been using these drugs and so essentially -- again, the doctors, the healthcare, they are learning a lot from us but we are suffering potentially life-threatening and life debilitating illnesses from some of the side effects of these drugs and the way that they work.

I've not looked into chemistry, I do not know how they work, but I know they have been destructive to some people. I believe there's not enough screening of potential long-term, the potential long-term implications of the drugs, although, you know, I'm looked after very well at my Haemophilia Centre, which also manages my HIV care and I always thought that. I always thought, "I'm safe here. They won't let anything happen to me", but it already has. My kidney issues, the heart artery issues and, I mean, I always said to my wife, "At least my heart's good, you know, we can count on that", but I can't. So,

again, it's not enough screening of potential long-term implications of these drugs, I feel.

Q. The second point that Ms Monaghan has asked me to raises is something that happened during your last hospital stay. There was a life-threatening error of some kind that was questioned by your wife.

A. So that actually falls into two different categories actually. At the moment there's a new product for haemophiliacs, a new wonder drug like Factor VIII was heralded in the '70s, a wonder drug.

Now, my Haemophilia Centre wanted me to start this new drug. It basically it will clot my blood for a week at a time. So I will need -- and I won't bleed -- it's an amazing new dug. They were pushing for me to have this, I think it was at the beginning of 2018 and, obviously, now we know I have these issues with my arteries in my heart.

If they had given me this is new drug then I would have had a heart attack on the spot and died because, as I say, it clots your blood pretty much immediately for up to seven days or more.

Now, once I would have infused this drug there wouldn't have been a way to clear my body of it or not easily anyway. But because of the arterial damage I had, I would have dropped dead basically as soon as

injecting it.

Also, the other issue I had when I was in hospital having my open heart surgery, there was an incident while I was an in-patient with my clotting medication. It's a medication called Factor VIIA or NovoSeven and when I have operations or -- I've got an inhibitor, so I use different clotting factors to someone without an inhibitor, and this Factor VIIA was given to me over 24 hours on a syringe pump driver similar to a drip but an incident happened with that in IOR, that's intensive overnight recovery, with very highly trained nurses, one-to-one care and it's, you know, supposed to be one of the safe this places in hospital.

The pump that was being used to infuse me with my blood clotting medication, there was an issue and when pumps or drips have an issue they sound an alarm. The alarm sounded. I mean, I wasn't aware of this because I was asleep but I know more of the facts now. The alarm sounded, my nurse came over and just silenced the alarm and he didn't check why it wasn't working properly. The alarm sounded a further two times -- so three times maximum -- and then he unplugged the machine. I've no idea why he unplugged the machine. All I can think is he was fed up

listening to it. I don't know, he was very busy and didn't want to deal with me, even though I had one-to-one care with this nurse?

So I went a whole night without having any life-saving medication. I had no blood clotting medication for about eight or nine hours and I then bled profusely. I bled internally into my chest and needed to be opened up -- I think this was the third time -- for them to clear out all the blood and my lung collapsed because of the amount of blood in my chest was pressing against my lung.

That's negligence. That's disgusting behaviour, in my opinion. A highly trained nurse giving me one-to-one care just deciding to turn the machine off, it makes no sense to me at all. So I am -- me and my wife are following proceedings to find out what happened.

Q. Those are the questions that I have for you. Is there anything that you would like to add?

A. To be honest, I feel I've covered everything I wanted to. As I said, I'm scared for the future. Well, I'm scared for the future of my wife and child. They just live off of my finances. If, you know, anything happens to me in a year's time, a couple of years' time, I don't know *(unclear: interference)* exactly how they would survive. My wife's been severely affected by all of the implications *(unclear: interference)* last few years and has quite serious anxiety and her own mental health has been affected by this issue. Apart from being scared for myself, I'm scared for my wife and child if I was to die, basically, and, you know, I can't emphasise enough the impact of having two viruses.

It's just ... it's affected me -- it's affected me in a way that -- you know, even I didn't think they could from becoming undetectable to HIV when I was 21 and believing that life was going to be better from then on, it's not been. It's been incredibly difficult because of the stress my body's been under, the multiple illnesses I've had over the years. I just don't think it's going to end. I'm lucky to have a very supportive wife and a fantastic daughter and my whole family supporting me.

Q. Thank you.

Sir Brian?

SIR BRIAN LANGSTAFF: It was important evidence to hear your story for someone as anxious as you are. Having overcome so many difficulties and challenges, it has been particularly impressive that you felt able to come here and give it and for that I am really very thankful. Thank you.

A. Thank you very much.

MS RICHARDS: If we can cut the video link now.

SIR BRIAN LANGSTAFF: There is one I thing need to say before we break and we will break until 2.45. For those of you who heard a name being mentioned earlier in the evidence, you must remember that to you he is, and will, remain Mr AH. Thank you very much.

(2.31 pm)

(A short break)

(2.47 pm)

SIR BRIAN LANGSTAFF: Our next witness will be known as AI it follows on the order from AH and in his case I make an anonymity restriction order in these terms.

I order that the name and address of witness W0008 (that's AI to you and I) the name of any member of the witness's family and other identifying information such as the witness's image or a description of their appearance cannot be disclosed or published in any form unless express permission is given by me or the solicitor to the Inquiry acting on my behalf. Witness W0008 must be referred to only as Mr AI.

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

Mr AI, would you come forward, please.

MR AI, affirmed

Questioned by MS RICHARDS

Q. You were diagnosed with severe haemophilia A when you were a baby in 1980?

A. Yes.

Q. And you were treated thereafter at the Birmingham Children's Hospital under the care of Dr Frank Hill until you were 17 and then you transferred to the Queen Elizabeth Hospital, also in Birmingham.

A. That's right, yes.

Q. Now, when you were very young you had a lot of bleeding episodes?

A. I did, yes.

Q. Three to five a week you have suggested in your statement.

A. That's right, yes. I would be treated quite often because of multiple problems, often surrounding my ankles to begin with but as I grew, I had an awful lot of bleeds related to my growing. At the time we would be having to call ambulances to be taken to the hospital where they would treat me there to begin with until my mother was introduced to treating me and later on having to learn how to treat myself.

Q. Your records show that you were first given Factor VIII products in October of 1980, again as a baby. You were given cryoprecipitate for a period between 1981 and 1982 and then back to Factor VIII products.

A. That's what I'm told my records show, yes.

Q. Then in terms of the home treatment, that began to be administered, first of all, by your mother in 1986.

A. Yes.

Q. And by the age of 7 you were --

A. I started to learn to do it myself as well. During that time, my mother would also be treating me alternating because, after having the brain haemorrhage I had, I was paralysed down my one side, so I don't have the co-ordination to do it both ways, so my mother would have one arm and we'd alternate who did it so it would be on this day I would do one and then my mother would do it two days later, let's say, using the other hand to let my veins rest.

Q. Now, were your parents, as far as you are aware, ever given any information or advice or warnings about any risk of infection associated with the use of the factor products?

A. No, they were told that the -- what I was on would be heat-treated. This is after my cousin had already been infected and that was in 1984.

So after that had happened to our family, both my mother and his mother were told at the haemophilia unit that now they'd started using heat-treated products and once they started that they said it was absolutely safe. Things like that couldn't happen again. So at that time I wasn't infected and my parents were told it was not possible to be infected after -- once you're using the heat-treated products.

Q. If we just take it in stages. So before heat treatment was introduced, before your cousin was diagnosed, from 1980 up until 1984 when your cousin was diagnosed as having been infected with HIV, you were receiving Factor VIII during that time, Armour products, as far as you know?

A. Yes.

Q. Were your parents told in the pre-heat treatment phase anything about any risks?

A. I don't know what my parents were told at that stage about potential risks but I don't believe they were told that they were taking any risks with my health. If they were told anything, they were told it was as safe as it could be and that's all I've never been told that they were -- that was said to them at that time.

Q. And then as you've already referred to, in 1984, it was discovered that your cousin, who was very similar age to you, I think six weeks older than you --

A. Six weeks apart, we were.

Q. He was four at the time and the family was told that he had been infected with HIV.

A. Yes.

Q. But you were tested and at this point you had not been infected with HIV.

A. That's right, yes.

Q. The test results were negative.

A. Yes.

Q. Then as you have just said --

A. Sorry, the testing was happening quite often after that stage, once they'd established that some had been infected. I don't know how many other episodes prior to my cousin's infection episode, the incident that infected him, and I don't know how many others it infected at that time, but I don't know how many other incidents of other infection times they had already had.

But I do know that from that time onwards we were being regularly tested. I know this now and my parents will have been taking me to the hospital, after the fact that my cousin was infected they were obviously furious and then very scared for my well-being. So testing will have been taking place and for a long time I was clear of the viruses myself, and that's when they were telling my parents that they'd taken the precautious that they needed to, what they were using now was much cleaner and heat treated, therefore, it couldn't happen to me after the fact of my cousin's infection.

Q. What you have said in your statement is your parents were reassured by the hospital that heat-treating the blood products was now being done and so you could never be infected in the same way, the products would be safe and free of viruses?

A. Yes, that's what they were told. They said the entire point of the heat treating is to get rid of the viruses. If there was ever anything like that in the products, it would kill them.

Q. You had contracted hepatitis B --

A. Yes.

Q. -- in early 1985 when you were about four years old but you naturally cleared that virus.

A. Yes. That was during the time I was still at the children's hospital that I actually naturally cleared it.

Q. Then in around August or September of 1986, your father was told by the hospital that there was a problem with a batch of product?

A. Yes, that they'd been giving to me and that they -- I don't know how it was explained to my parents. I know that my father wrote at the time about what he'd been told and how they were told. I do know that my mother was told eventually that I was infected over the telephone.

Q. We'll come on to that. Again, we'll take it in stages.

A. Okay.

Q. Around August or September of 1986 there was a recall of an Armour product your father was told and, as you say, your father wrote a letter and we're going to look at that.

Paul it is 0008004, please.

We can see the date of it. It's 14 November 1986. It refers to you and -- you being a severe haemophiliac.

A. Yes.

Q. Then it says this in the second paragraph:

"There are over 100 young patients receiving treatment at the Children's Hospital Birmingham and each were recalled and tested for the virus. Unfortunately, a large percentage were found to be already carrying the AIDS antibody. It was then announced that the Factor VIII was to go through another process by which it was heat treated and, of course, we thought our worries were over. Not so, two patients were found to have contracted the antibody even after this safeguard. Our fears have returned and we no longer feel secure using the above mentioned product."

Which was -- in the first paragraph it mentions it's Armour. Then over the page your father continues:

"Following this the hospital called in Armour Factor VIII and we were issued with a product made by Alpha."

Then it says:

"At the present [and names you] is free from the virus but he has to have fortnightly blood tests to keep check on his condition. Obviously this lack of guarantee of what is the life saving product worries us, as you will well imagine."

Then if we just go down towards the bottom of the page your father says this:

"We understand that we could well produce

Factor VIII here in Elstree but sadly the Government fails to fund to a correct level to make this country self-sufficient. Although at present we produce a limited amount, funding to a higher level could give us all peace of mind. Dr Hill, the head of haematology at the Children's Hospital says we need urgent resources to fund the following: (1) research to produce a synthetic Factor VIII which would be 100 per cent safe; (2) for health education; (3) for a counselling service so necessary particularly at the present when all the patients and their relatives are at their lowest ebb. At present we haven't a single counsellor either at the Children's or at the Queen Elizabeth where the young patients continue their screening and treatment after reaching 16 years. We can only wait for our twice-yearly consultation with Dr Hill. It is quite dreadful that we can't get advice when we are all so anxious. The only way we can get this much needed chance to talk through a particular problem is through the parents' self-help group."

That, for the sake of completeness, was a letter that was being written to your local MP Peter Snape.

That is 14 November 1986. Up until that point, you had tested negative of the virus.

A. Yes.

Q. But that changed and your records suggest that you first tested positive on 19 November 1986 --

A. Yes.

Q. -- only a few days after that letter was written.

A. So they worked out later that it was probable at the time that was being written I'd already received the treatments that were infected. So my parents are thinking I might have dodged a bullet if you like and they are writing with hope and it wasn't long after that, although there were, I now understand there were unacceptable ways that they found out about the fact that I'd been infected, at that point they didn't think I had been and I feel for them.

Q. Your understanding from what is set out in your medical records is that you sera converted in around October/November 1986 when you were six years old?

A. Yes.

Q. And critically at a point in time at which the only product that could have infected you with the HIV virus were the heat-treated Armour products that you had been receiving.

A. Yes, at the time the batch numbers of what I was being treated with were being recorded by the hospital, which I've managed to keep -- get a list of to

yourselves to show that it was those products that I was on at the time. So, as far as I understand it, it can only have come from that source.

Q. We can see from a statement that your father made in subsequent litigation -- Paul, it is 008009, please -- this is a statement prepared by your father I think for the purposes of either the HIV haemophilia litigation or litigation that was taken against Armour itself but we can see about halfway down the page it says:

"In about August 1986 I was informed by the hospital that a particular batch of Armour heat-treated product was faulty and that there was some sort of problem. I received instructions from the hospital to return all the remaining supplies of heat treated Armour Factor VIII to them. After the product had been returned [you, Mr AI] had to attend hospital approximately once every fortnight for blood tests. My wife has informed me that on one occasion she went to the hospital and managed to catch sight of the file in relation to you. The file indicated that the results of the fortnightly tests had proved negative up until November 19, 1986, when the word 'HIV positive' was indicated next to the results of the test. We were not actually informed of the position until January 1987. To the best of my knowledge and recollection the only treatment our son ever received was with un-heat-treated and heat-treated Armour Factor VIII. He most definitely sera-converted at a time when he was receiving the heat-treated product."

That was the statement your father gave in the litigation.

A. Yes.

Q. The reference to your parents not actually being informed of your diagnosis until January 1987 is a reference to a telephone call your mother received. What can you tell us about that?

A. Yes, my mother, when this was explained to me when I started to become a lot older, I would be around about 15 to about 17 when I was told more, but my mother explained to me that one of the things that really hurt them and angered them was that she was only told over the phone and it stressed her massively, to which point they immediately fled up the hospital with me to try and find out what the hell had gone on and how it was that they'd been -- it wasn't just being told over the phone. It was the extent of everything she'd already read, I now understand this information was kept in these boxes for years and

because I was so young I wasn't aware of all the information found out at the time until much later and it's only in recent months even that I've ever seen this document from my father and my father's statement.

I didn't know the details of how it was that they were told over the phone and I didn't know that it was months later that they actually had been informed that I'd actually become HIV positive.

So obviously the more I find out about it the more upset I become about how they were treated and how they were told what had happened to me. So although I don't know because I was very young, I was six, so because I was that young I didn't know what was happening and I think my Dad references in one of his letters that they didn't tell me that I was HIV positive to try to shield me from the strain of that, given that it's becoming a very famous deadly disease and they didn't tell me until I was older but whilst I'm at school they were telling me to have to be very careful how I play with other children.

Trying to move the focus on to remember you're a haemophiliac you might hurt yourself, but I then later in life come to understand we were also protecting the other children and that's why I'm not

doing sport or physical activities with the other kids, just in case there is any kind of school ground accidents that would threaten the other kids. So I can imagine they were deeply stressed with wherever I was, whenever I was out of sight.

Q. You have described it in your statement as, as you got a little older, your parents essentially broke the news to you in stages?

A. Yes.

Q. First of all, you've got something in your blood. It means other people can't touch your blood. You need to be very careful when you are playing with your friends.

A. Yes, when I was relatively -- at the beginning I would probably be about 13 when that was proposed to me.

Q. Then they said to you a little later on you needed to be very careful in PE and careful of accidents.

A. Yes, that would be at school, in junior school. That was when I was younger.

Q. Then you say it was when you were aged some time between 14 and 16, so your mid-teens, when you finally were informed and understood that you had HIV?

A. HIV, yes.

Q. You had also been diagnosed with hepatitis C?

A. Yes. What I understand of that is I wasn't actually

tested and diagnosed until the early '90s and I understand that -- I believe that to be because the testing wasn't available until that period. So although it all stemmed back to the dirty products that we were given, I believe we weren't confirmed as having hep C until later because the testing wasn't available. That's as far as I can recall.

I do remember my mother telling me that but I don't -- I didn't know what year specifically, whether it was 1993 or 1992 that she remembered that it was asserted when I was finally diagnosed with that as well.

What I do remember about that is that she pointed out that my cousin didn't get that but that may have been because my cousin died in 1992 when we were both 12, so it may have been that he hadn't had the test yet but I don't know. I do know there was something I got which I believe was the hep C that he didn't get diagnosed with but I think that may be because he died.

Q. As you say your cousin died at the age of 12 years old --

A. Yes.

Q. -- from AIDS?

A. Yes, he developed double pneumonia and died because his immune system collapsed.

Q. You yourself in terms of the hepatitis C cleared it naturally when you were in your late teens.

A. Yes. I would have been about 18 to 19 when they told me that because I know that I'd already transferred to the Queen Elizabeth Hospital by that time and I didn't transfer to the Queen Elizabeth Hospital until I was 17. It was normal that you went earlier but because we were haemophiliacs and the bond with where we were being treated was quite strong, a lot of haemophiliacs didn't transfer until they were a little older so that there was a better picture of how -- where our health was before we moved over, so I will have been 18 or 19 by the time they tell me that I've naturally cleared the hep C.

Q. There's a long-term health consequence of the hep C which we will come on to at a later stage.

A. Yes.

Q. You have said in your statement that by the time you transferred to the Queen Elizabeth Hospital you were receiving what you have described as a proper education from the hospital about HIV and hepatitis and what it could do and you understood about transmission and risks of transmission.

A. Yes.

Q. You were given, you have said, at the Queen Elizabeth Hospital very helpful advice in relation to sexual partners, taking precautions and they were very supportive and didn't try and discourage you from forming normal relationships.

A. That's correct. Everything that I learned about living with it, and the goal was not to necessarily let it completely destroy your life, came from help I got from both my social worker which I was put in touch with as soon as I came to the Queen Elizabeth Hospital, and I'll explain the importance of that later and also at the Queen Elizabeth Hospital, the staff there were used to dealing with the patients as adults, no longer as children as you would be spoken to at the Children's Hospital.

Although they did see us as becoming adults, they'd spent years dealing with your parents and explaining things to them and then it developed into you'd have things explained to you together but they are really more talking to your parents to make sure that it's kept straightforward.

At the Queen Elizabeth Hospital, they immediately are speaking to you as an adult and they did have some significant differences in philosophy as regards how they dealt with you. So you were immediately talked to as an adult and my social worker's help, because I had a lot of trouble with staying at school and social interaction, was -- it was critically important to me and it was how I understood how do you live with this deadly virus and how do you protect other people. It wasn't just about things like becoming adult and becoming sexually responsible, it was obviously you fantasise -- having a bleeding disorder, any accident like a crash or anything threatens everybody else, so you're always wanting to know the extremes of the precautions you need to take.

So we had to learn how to behave as adults with the viruses.

Q. I know you wanted to say a little about your cousin because there's no-one else to speak for him.

A. Yes.

Q. He was just 12 when he died.

A. Yes, he was infected when he was four years old. We were both four, and at that date they infected my cousin and he didn't survive that long more than the Government's guideline time-frame which was something like five years. My cousin made it to 12 years old and he developed a cold at school which then developed into a much worse form of flu-like symptoms and then that escalated into double pneumonia and that's what he died of.

I do remember both going to the hospital when he was dying and, basically, being told to say goodbye, and also at school there was a vigil at the school where everybody was encouraged to hold a candle because my cousin had died and they'd all been told but obviously not been told why.

Q. You yourself didn't know the exact reasons why he died at the time because you were only 12.

A. At the time I didn't know what was wrong but I found out later, you see.

Q. You found out what he died of at the time you were being told that you had the very same condition.

A. Yes, I was not told at the time he died that he died because he was HIV positive, because I was also HIV positive and my parents were trying to protect me, but I was told that he died of double pneumonia. I wasn't told why that was.

So I knew at that stage that he'd become really ill and died but I didn't find out until I was older when it's been explained to me that I am also HIV positive and that was the reason my cousin had died of what he died of. So obviously that impacted me quite hard because you then think, well, if that's how extreme things can get and how fast it was, what can you do with that?

You just are waiting for something random because my cousin -- it didn't take him long to become that sick. One thing that was the case at that time, I was not on treatment for HIV when I was at the Children's Hospital and I would believe that that would mean that my cousin wasn't, because the reasoning there was because at that time there were only the very early drugs for the HIV, they would tell us that they would only keep, I found out later in the years, round about 17, round about the age of 17, that they tended to only keep the treatments for when things got really bad because they didn't want us becoming resistant to them. That was the mindset of the Children's Hospital.

However, when I transferred to the Queen Elizabeth Hospital, their philosophy was completely different and I was put on treatment immediately as soon as I got there, so the difference in the style of the way you were treated was completely different.

I don't know whether anything they could have treated my cousin with could have helped him to not become sick in way he did because I do not know what of those drugs was available when we were both

12 years old in '92 but I do know that if they had anything, is it AZT was the very early form of treatment that they could use, but I think that would be the only thing they could have possibly done to try to help him but there was nothing they could do to help him at all. His mother was obviously destroyed by that.

Q. You have described in your statement once you became aware of the diagnosis and you began to understand the implications of it, you've put it this way, that you began to build mental walls. You thought you were dangerous and you became terrified of infecting others?

A. Yes. Initially, because I wasn't sexually active it was just the point of view of interacting with other people, and one of the things I did do because I wasn't very capable but one of the things I did do was I did voluntary conservation work for a short time until the bleeding issues that I got were causing too much trouble and it had to stop. But during one of the episodes I was working with them, I managed to cut my hand whilst we were working on some of the coppicing we were doing and at that time I remember a medical staff member coming towards me trying to help me and I ended up kicking him away from me

because I was worried about him.

Q. You were frightened that if he helped you you might infect him?

A. Well, we'd all been working with tools so I'm thinking he doesn't know if he's cut himself anywhere. So I'm extreming the situation. I don't want -- he wasn't wearing gloves and I didn't want him messing with me whilst he'd obviously been using the same kind of large blades that we were using on the trees if he had any kind of cuts on himself. He didn't know that I was HIV positive.

I told the office there and they were aware of it and were comfortable with me working with them but he himself didn't know, so I kept him away from me the only way I could. But it was basically my own built up walls and trying to keep it away from everybody else.

Q. You talked about having a breakdown at the age of 17 and until the age of 24 you became what you described as a very closed off person. You didn't leave the house.

A. I didn't go anywhere. I'd spend almost all my time in one room and it just was an easier way of dealing with everything. It's already difficult enough for us to socialise with everyone else given that we are

physically to damage ourselves being haemophiliacs and keeping up with the normal pace of normal people always injures us, but as I grew up and I start building barriers between me other people as far as, getting girls and girlfriends there was just nowhere I could go in my mind to justify going along that path. So yes, I became very closed off from everybody and eventually it was even disruptive to my family.

Q. In terms of the physical effects you have talked in your statement about feeling seriously fatigued all the time, constantly being on drugs with side effects. Can you tell us a little about that?

A. Yes, you see, a lot of the drugs we have to take are very toxic, so you're always dealing with extreme levels of nausea just with -- and you're having to take anti-sickness pills just to combat the nausea, just so that you can eat, because you are endlessly feeling nauseous. But you are also weak and drained because they basically knock you about. It's almost like they toxify you to toxify the virus enough to keep it down.

I don't know how it works but it seems to have to beat you up in order to combat the virus and I've heard it described many times as like being on a mild form of chemotherapy all the time because you're so wiped out, you're tired, you feel sick all the time and it really affects your ability to have any energy whatsoever and, on top of what we're already doing, it just makes life three times as hard.

Q. You had recurrent serious infections that required you to be hospitalised over the years.

A. Yes, I had several occasions where I would have to go into hospital because I developed some kind of lung infection or something similar where I would be choking up whatever this infection was. But what would often happen, it wasn't every single time, but it often was the case that they couldn't even diagnose it and the policy at the time, for example, with antibiotics is if we can't diagnose it then we can't work out which type of antibiotic you can be treated with, therefore, we can't provide you any treatment.

So several times I was in hospital they would just leave me there and hope I'd get over it. I have actually signed myself out of the hospital because they were not willing to provide me any treatment and I was getting better care at home. That was purely policy-based.

Often it also had things to do with the weekend skeleton crew of staff they were having, no doctors around to intervene. But it was usually because they

couldn't tell us what it was. It wasn't a matter of waiting for the tests when they sent off samples. They said they didn't know what it was so that because -- they explain it because your HIV is so bizarre in what it can allow to happen to you, we can't diagnose every illness that we come across, so they would then not treat us and in my case they didn't treat me several times and I essentially just about got through what I was dealing with at those times.

I can tell you that happened -- four times I can remember distinctly when they couldn't diagnose what had happened to me. It was some kind of infection. I was coughing my guts out, not just coughing but literally bringing things up and there was nothing that they were able or willing to do.

Q. In July of 2005 you were diagnosed with B cell lymphoma cancer in your chest.

A. Yes.

Q. You understand that to be a direct result of the hepatitis C --

A. Hep C, it --

Q. -- or both infections?

A. It has to be related to the hep C but it could have had an impact from both because of my immune system

being shot to pieces. So although I did naturally clear the virus, the hep C virus, by that time, I found out later it is one of the things that hep C can lead to and, as regards The Skipton Fund, it's one of the illnesses that they accept that you will and can suffer having been infected with hep C as well.

So I believe it to be very much related to the hep C and, obviously, my HIV impacts everything.

Q. You had to undergo chemotherapy?

A. Yes.

Q. Because of the B cell lymphoma and you started that pretty much straight away after the diagnosis in July.

A. Yes, as soon as they could get me into it. I had to have five courses of the chemotherapy. I was supposed to have six but the sixth course, during the testing they said that the levels of the test that they were doing, which was showing how stable my own condition was, if I had had the sixth set it would have killed me. So I was unable to have the sixth set and they basically just had to wing it whether I would get through it or not. They didn't know whether I would survive it because the cancer I had was -- when they started the chemo it was 11 cms across inside my chest. They said it was like a large orange in there.

The chemo I was doing was both intravenous and

also through lumbar punctures into my spine and each time I went there, there were five sets that I had and I believe three of them were lumbar punctures.

So later on we'll explain that that had its problems. It caused problems for me later. But I did get through it, but it was blind luck. They said that -- they weren't even remotely sure it would be enough because it wasn't gone by the fifth stage but, fortunately enough, it had shrunk enough after that fifth stage for me to get away with not having the last cycle.

Q. In terms of treatment for HIV, you're on a triple therapy treatment but you have had problems with the treatment over recent years because you've become resistant to particular medications and combinations have had to be changed.

A. Yes, I'm told there are four groups of treatment that can be provided -- not four independent drugs, it's groups of drugs and I am now resistant to one whole section and then half of another section. So, as I explained to you, what that means to me is I'm running out of options. It means that I keep becoming more and more resistant to what is available and that cuts down what they are able to treat me with. It doesn't matter what drugs are available if you are resistant to those drugs because it won't work anymore.

So, yes, I do feel like I'm running out of time, if you like, as regards what will help me suppress the virus.

Q. You have experienced side effects from the drugs in previous years.

A. I've had some amazingly difficult times having been taken off one drug that they call getting old or less efficient often because they are saying I'm beginning to become slightly resistant to it and they have a newer drug that they think will work better.

One of the episodes I had with that was I developed a major form of migraine because I had just gone on to this one new drug and it was called efavirenz and I developed an immense type of migraine that initially floored me. I then had to be taken back to the QE, they booked me in and they had to take me off my pills under my insistence that this new pill had to be *why*.

There is a culture of, "Don't be silly, it can't be the drugs, the drugs do no wrong", within hospitals. They are very positive towards the form of treatment you are on but I was adamant because it was the only new thing I'd done that it had to be that and

they did take me off the drug and although I did have one additional spike of the major migraine I've got -- I'm lying in the hospital bed with a latex glove filled with ice on my head just so that I can open my eyes and I was like that for days and although it flared up once more, once they took me off that drug, it went away. So we confirmed that I couldn't tolerate that drug and this was all about trying to modernise the treatment I was on when they were moving things around and changing what drugs I was on.

Some of it is because I had become resistant to other forms, some it's because these were newer drugs at the time. But, yes, I've had major problems with a lot the drugs, even in more recent times.

Q. To the extent that there was approximately a five-year period 2000 to 2005 when you took no HIV medication at all.

A. I decided to come off the treatment at that time because I was being beaten up far too much by the treatment. I was zombie-fied by it. It was so aggressive that I had no life because of it. The only way I can explain to you, it was like going on holiday. As soon as I come off the treatment, which I did. I decided I just couldn't continue taking things that were being so hostile and it was against

my doctor's advice at the time but I told them this is wiping me out and I had to come off it and I was off treatment for five years, and during that time, believe it or not, it was completely free and it was like I was a different person. It's only then that I've realised how badly affected I was on the treatments.

Q. You went back on to the HIV treatment in 2005 because you met your partner, now wife.

A. What happened was, basically, simply because I met my wife, my equation -- let me put it that way -- in my mind changed completely. All of a sudden it becomes about protecting someone else. That's all I was concerned about. So I'd basically somewhat given up prior to that. I'd had enough. But when I met *[my wife]* I just needed to change what I was doing because it then isn't just about me. Even if we're not together it affects someone else directly, so there was a massive need to change what I was doing.

Q. You have talked in your statement about how -- and we've touched on it already but I just wanted to ask you a little more -- how you lived life like a hermit as a form of self-protection.

A. Yes.

Q. You would push friends away because you feared things

would go wrong for them.

A. Yes. Every time I had made friends eventually I became a burden to them. I'd had -- at school I didn't really make that many friends but I was always one of the disabled kids in the class so everybody was nice to you.

But after school when you are developing your own friends, whenever they would arrange to do anything or go anywhere I would be invited because I was part of their group but in some way I'd ruin it. Something would always happen that either stopped me going there or I would break whilst with them and be a burden because they were trying -- for example, just normally going out with people I am physically breaking down and they are having to rush to where they are going and I'm slowing everybody down. But I'm also carrying, if we went anywhere big, I'm carrying lots of medication with me as well which doubles the workload for everyone and I have gone to places where my friends have had to pack all my gear away because I've been taken away in an ambulance and they have been left to clean up my mess.

So whenever I would try to go anywhere with anyone, something about my health would destroy everything.

So I ended up basically just not interacting with everybody because I am a problem to everyone. So I spent years just in my bedroom staying there because it was the least problem I was.

Q. You've been with your wife now for a number of years.

A. Yes. That did change my life significantly --

Q. You have described --

A. -- with that support.

Q. You have described her as a godsend to you. She's taken on trying to get you out.

A. Yes.

Q. And getting you to interact more but you don't -- you still don't leave the house unless you are with her?

A. That's it. I still am only interacting with outside because I'm taken to places and it's very purposeful. It's still not let's go and have a nice time because -- well, apart from my social problems because of isolating myself for so long and the reasoning behind having to have a social worker because I interact badly because I spent years being really locked away, so I don't friendship well, if you want to put it that way, it's -- there's so many problems that I'm dealing with that whenever I go anywhere it's designed behind get what you are going to it and then come back and when my wife's tried to make it so that

I could be more outgoing but I'm still immensely reluctant all the time because I'm expecting problems all the time.

Even doing this has been a huge stressful task. So we never know what's coming. I've got a whole suitcase full of medical equipment full of just-in-case possibilities just because I've come to this and I'm always thinking about the times when I've gone places and that's resulted in -- just because I went I've ended up in hospital. Whether it's because I'm interacting with people and picking things up or whether it is the other side, which is the haemophilia side, with your body breaking down because you are trying to do what everybody else is doing. That led to me using a mobility scooter, which we'll talk about.

Q. You've said in your statement that when you and your wife do go out it's really, as well as having a purpose to it, it's a short trip so you will go to the bank or the shopping centre and then you go back home.

A. It's like a straight line journey. I know that that's difficult for *[my wife]* because *[my wife]* would prefer to explore more but I don't want to be there. I'm always thinking back to safe zone. So it's always

been socially really awkward and difficult and the more I know that it's because of the way I close myself off, but it's the -- the only way to explain it is it's the only place everything is safe. I can deal with what happens to me so long as it's just me, but when it's affecting other people I become immensely strained by it.

Q. The fact that you have made a much longer journey to come here to give evidence is a very unusual occurrence for you?

A. Yes. Yes, I don't normally go out. When -- my wife goes out for herself with her friends whenever it is arranged for them. I don't go with her and I don't interact with anyone. I had had friend groups but over time every time you dent what they're doing because you then become ill in the middle of it and then just become a problem, you stop being willing to burden them with what you deal with.

I've ruined several trips for a lot of people, including my parents, trying to carry me as part of whatever your group is, whether it was my family or those friends I had back then, eventually erodes their ability to -- well, it really erodes my willingness to put them through it and eventually I just gave up on it all and shut myself away.

Q. One of the individuals who has been very important to you in terms of providing you with practical support and assistance is the social worker who you've mentioned. Your statement describes a number of significant practical interventions by the social worker Mark Simmons based at the Queen Elizabeth Hospital in Birmingham, from helping you to get a flat that you and your wife could move into together, through to assisting you with applications to the schemes, which we will come back to --

A. Yes.

Q. -- and providing general everyday support and advice.

A. Yes. My social worker was golden. He was the only way for me to have any kind of independence because I'd boxed myself into a single room box and his entire motivation was trying to help me out of that cage I put myself in and he not only helped me with my wife but it started well before that, from the age of 17 onwards when I first met him, he saw immediately that I was hiding from the world and tried to get me to interact in a normal way with it.

He encouraged me into college and we did that for a few months until that was beaten up by my health. My health collapsed that idea too. Every time he's tried to do it it's also gone wrong but he was immensely vigilant and kept helping me with the normal instructions on what you do to have a normal life as an adult and, obviously, because I'm not outside interacting with other people, I'm not learning life skills. So he had to basically tutor me even down to basic fillings of forms of living in a home, what do you do, where do you send things, who do you get that information from, was all having to come through my social worker, aside from trying to deal with the schemes to do with this, which has been a nightmare in itself.

Q. In terms of family life, you have decided that you do not feel able to have children.

A. No.

Q. And you've put it in this way in your statement:

"My child not only could have haemophilia but could also carry and have to suffer the viruses and would still have to deal with a father that's a complete mess, a broken diseased thing. That's no life for any child. I would just never want to put any child through that."

A. I know some people would see that as unfair because a lot of people have gone on to have families but you tend to look internally and see nothing but episodes of trauma you cause everybody else, all of it really,

in your own mindset, you are used to damage.

That's what we do as haemophiliacs but with things like the viruses, when you become really sick it's abnormal. So everybody they see you bleeding and you've been dealing with that so everybody knows he's going to sort that out, he's going to get over the bleeding and he's going to be okay. But when you become sick, everybody is intensely frightened because you expect to die because you keep hearing that everybody else did. Your cousin did. My cousin *[redacted]* died and that was a random, what started out as a small thing. He was just a little bit snivelly and then very soon after he'd died of double pneumonia.

So every time something happens like that, you affect everyone else. So when I'm thinking of things like children, all I can see is what dealing with me would be for even if the kid was healthy and I don't want to put anybody else through what I've done. I just don't.

Q. You have talked in your statement, as well as the assistance you received from the haemophilia unit-based social worker, you also received assistance from the haemophilia unit community nurse, but certainly at the time you were drafting your statement

you said that both those positions were currently unfilled at the haemophilia unit due to financial and staffing issues.

A. Yes. It's both that the social worker I had had to retire because he wasn't well and the main problem that they suffered is the position of being a social worker to us is so immensely complicated that they can't actually train someone to deal with the years of information that they need to absorb to deal with both the illnesses we have but the trusts that are associated with our support, as well as having to deal with our disability benefits such as the PIP changes as well as any understanding of grants that we might be able to get help from from things like the council.

All of that information plus the medical damages that we've sustained becomes impossible for somebody to be trained. That's how it's been explained to me. They can't train someone with all that information and each time they've tried the person they were trying to get to do it has gone away.

But they are also under the pressure all the time of because they haven't filled the position, the overheads of the unit who -- not those who run the unit but those who fund it say, "Well, clearly you're not using one so you don't need one so we want to

close the position down".

So for at least ten years they've been under threat of losing not just those positions, the community nurse at the moment has gone because of the staffing level has been taken away so they don't have anybody who can act as the community nurse anymore and the social worker became ill and was never replaced. That left people like me lost, completely lost, because all of the information, the finding out how to interact with the rest of the world, came through my social worker and they won't replace them and it's been like that now for years.

Q. I want to just ask you a little about the litigation in which your parents were involved on your behalf and the issue of financial assistance.

Your father and mother wrote, as we've seen in 1986, to your local MP and continued to raise matters of concern with your local MP. One at least of those letters was passed to the then Minister for Health, Virginia Bottomley. If we just have up on screen the response your MP received, it's 0008003. It's a letter 16 November 1990 from Virginia Bottomley. It is at the time of the court action, the HIV haemophilia litigation. It says this:

"Thank you for your letter of 29 October enclosing one for [Mr and Mrs X] about the current court action concerning haemophiliacs who have contracted the AIDS virus. First, there is no argument about the scale of the tragedy or the desperate plight of haemophiliacs infected with the HIV/AIDS virus. It's difficult to find words to describe the depth of the distress which both they and their families must be experiencing. The Government has never disputed our moral responsibility to pay attention to the needs of the victims and their families. We have quite uniquely paid haemophiliacs with HIV at least £20,000 each to help with their problems and we have paid more in cases of hardship. We have also always promised to keep the sums available to the Macfarlane Trust and the needs of haemophiliacs under review. Despite our promise to keep under review the £34 million already made available many haemophiliacs have decided to pursue legal proceedings alleging negligence against the last Government, the present Government, the licensing authorities, the health authorities, and the doctors who treated them. On the information before me, I have no grounds for conceding the tragedy was the fault of the NHS or of this or previous governments."

She then talks about concepts of no fault

compensation and then if we go over the page please, says this:

"There have been no substantial changes in the basic arguments since then. While no fault schemes remove the perceived unfairness between those who can prove negligence and those who cannot, they create unfairness between those disabled as a result of a so-called medical accident and those who are equally disabled through natural causes. They also generally result in individual claimants receiving much smaller amounts of compensation than would be awarded through the courts in cases where negligence could be proved."

Then she says this:

"Our NHS is greatly threatened by the increase in the number of writs that are being issued claiming compensation for allegations of medical negligence. The American healthcare system is being ruined by excessive litigation and the mounting costs of compensation. It is possible to organise powerful emotional campaigns for many groups whose treatment has failed to restore good health. All medical treatment has an element of risk and involves considered judgments of those risks in the light of current scientific knowledge.

"I am sorry if this is a disappointing reply but

the Government is showing its great concern for haemophiliacs with HIV, by the *ex gratia* payments it is making. I am afraid that the question of compensation has to remain a matter for the courts to decide if some of the haemophiliacs insist on pressing their legal claim to a court hearing."

You wanted to draw that letter to the attention of the Inquiry and exhibited it to your statement. You have, I think, and you have expressed them in your statement, views on the amounts of money that were or were not made available to individuals through the *ex gratia* payments scheme?

A. Yes. I just -- to begin with, I would like to point out that I see them as radically unfair, if I understand them correctly, that someone who was a child would not have received as much as someone who was an adult or an adult with children because it doesn't account for the fact that we -- apart from the Government's point of view that we're all going to die in five years, which was thrown around at the time, you would expect that we would grow up to become adults and then expect to try to put some kind of life together that may include a partner and, for many, may include children.

But if we're to get less because we're children

at the time than people who were already adults, it just seems completely unfair. Obviously, the first thing everybody's going to say is essentially my cousin is put to death for what amounts to £20,000 and there isn't a soul on this planet that would put up with that, being told that's what your life's worth. Nobody would have that. Just in general the idiocy of the figure that they say makes up for what was done to us is absurd in itself. But then to treat us as children as somehow less worth than those who are already adults, although I accept that they have other responsibilities but we, as children, were going to become adults and have those problems and responsibilities ourselves. So the idea that you could give less to us because we were children just seems incredibly unfair and it's just -- it seems deliberately divisive between the groups of victims.

And you then -- I'm not going to call at any time resent -- becoming resentful of any other victims in other situations. That's not where we come from. But whenever anything has been arranged for any kind of payment system, there are always ways that divide us into groups that end up being unfair figures. It's from the litigation at the start to the support systems later on (where they separate off widows from what they call primary infected victims), there's always differences in the way they will fund it or huge differences in the amounts that you are allowed to get, and it's almost a divide and antagonise and ultimately to try to save money.

Q. You've made a number of observations in your statement about the schemes and indeed your own experiences with the schemes and I am just going to draw out some of the themes from that and ask you about them.

You have just touched on one of them which was the cessation of payments after death.

A. Yes. One of the most vulgar things that you have to deal with when you're applying to the trusts is their stance when a primary beneficiary dies. Basically, after one year of the payments -- after one year after your death, they stop all payments to your family and they basically cross your name off a list, say, "He's not alive anymore so we don't have to pay them. It doesn't matter what happens to them now".

I've always found that to be amazingly unfair because you leave a family in immense grief. I know this for a fact because I know that my aunt would have been essentially cut off because of the policies made up by these so-called supportive trust funds and I'm left watching that and thinking every time you've paid

me, that means something that you've refused to pay the families of those who have died. So they will be left with nothing but their grief, their anger and their pain with no support whatsoever.

So no, it's not okay that entire groups get completely cut off from systems that claim they are there to support the victims, even though all of those victims, whether they are parents, widows, or you as a primary infected person are also supposed to be named in the deed of the trusts themselves. It was supposed to be set up to support haemophiliacs that had been infected with the HIV virus in the case of the Macfarlane Trust, who had been infected via blood products from the NHS, but also to their families, the families of those people who have been infected. So your parents were supposed -- were named specifically as supposed to be supported, the widows were supposed to be supported all in this deed, and yet the Trust itself, when you get into what happens when you die, cuts them off and I don't understand how that's okay.

Q. In that regard, you have also drawn attention in your statement to disparities between the current system and the position in Scotland.

A. Yes. When the change to the EIBSS was proposed, we were sent letters which amounted to the

Macfarlane Trust pleading for its life really but what they were highlighting was if it comes to pass that this new scheme is set up, it would be found out by the Haemophilia Society as well that the Scottish system would pay a great deal more both to primary beneficiaries and to widowed beneficiaries in the amounts. The Scottish system would pay a hell of a lot more than per month in their payments than would happen in the English system.

So basically you're getting a lot less money if you live in England just because you live in England. And I also understand that the Scottish system proposed that widows would get I believe it said 75 per cent, at the time this was all being proposed, of the payments of a primary beneficiary as an ongoing payment, acknowledging that the dead victim was a living person who had a right to life. So at least their family would be receiving something that could help them through not just their grief but their financial hardship, losing somebody who -- essentially we all received money, so it could stabilise our lives. So when we are dead, that's suddenly gone as well from that family.

So in Scotland they would receive that 75 per cent of the payment. As I've said before, I will not get into whether the amounts are acceptable. I'm talking about them receiving a payment that can keep them perhaps financially stable through their grief but in England you get a one-off payment when you die under the new scheme. It's not just that they cut you off, there's a one-off payment, a small amount (I believe it's something like £10,000) and then that's it. Forget about you. It doesn't matter who the person was that died.

So in England it's completely unfair compared with an ongoing payment that happens in Scotland and the difference between the two is just brutally unfair. So I don't see anything as more wrong.

Q. You have some particular concerns about the processes and transparency of those processes that you have identified in your statement. You've talked in your statement about how in the early years of the Macfarlane Trust your mother wasn't made aware of the possibility of applying for grants, and it was only later when the social worker that you've mentioned told you and told you also that he had to tell a number of people about the availability of those grants?

A. Yes. We had no idea and I say "we" because I didn't have a clue either. My mother wasn't told they did a wide range of grants. We're talking about when I'm 17.

When I first met this social worker, who has enlightened me to the fact that we haven't received any support from what they call the grant system within the Macfarlane Trust, despite the fact that apparently we were supposed to be able to access this ever since the MFT had been put in place.

So my parents had done without grants. My mother said she did once find out that they did a washing machine but when they applied for it, it was made absolute hell for them for having to jump through hoops to try to qualify and in the end they gave up. It was over.

So from that point onwards that would be in the very early days of the Trust, both my mother and father had no idea that they even did the wide range of grants that were available when we met Mark. And he had to educate me into not just how many things that we'd been doing without that my parents should have been receiving as support all that time and they -- my parents were poor. My father was worked for like £40 a day. So it would have made a massive difference to them and they just weren't made aware of it.

So when my social worker introduced me into it, he had to teach me what you had to do to apply for what was a wide range of different grants. It was never immense amounts of money but it was helpful if you don't have any.

At that time, it wasn't too difficult to apply. You just then had to provide things like a lot of receipts and sometimes slightly absurd levels of receipts to prove that you'd spent the money correctly because you weren't trusted. But it was support that my parents were essentially denied whilst looking after me as a child. They didn't know because no-one told them. The Trust itself never told anyone that these grant systems existed and that left them not knowing they should have been getting support.

So I again feel bad for my Mum and Dad, and I know that my aunt would have been cut out of any of that as well because my cousin died in '92.

Q. You had particular difficulties when you made an application to the Macfarlane Trust in 2015 for funding for a mobility scooter?

A. Yes.

Q. You say that was the most difficult experience you ever had with the Macfarlane Trust. You had to get medical letters to verify your need for the scooter,

which you got, but your application was still turned down.

A. Yes.

Q. And turned down on the basis that other organisations, such as the local authority, should fund this.

A. The initial one -- it ended up being a three-year battle in total which crossed over between when the Macfarlane Trust was taken over by the EIBSS.

I initially applied under the Macfarlane Trust rules during a period where they had made the ability to qualify for a grant a hell of a lot stricter under an undefinable phrase of "exceptional circumstances" which they refused to define to us. Bear in mind by this time I have been dealing with the Macfarlane Trust for a long time at that point. I believe we were in two thousand...

Q. Your statement suggests it was 2015 when you made your application for assistance.

A. So by 2015 we'd gone through a big change in the scheme where we had gotten the MFET payments, which were direct and automatic. But because they were direct and automatic payments, it was felt by the powers that be that we just shouldn't need the grants anymore and should stop getting them all the time.

So they made it immensely difficult for anyone

to get any access to a grant, but then we're still being told, "These grants are there for you. We do grants for mobility equipment. We do grants for medical modifications to your home for disability needs".

So I applied because I'd developed a lot of trouble from dealing with the cancer -- I'll explain why as I get to the later stage -- but I applied to them because they told me this was available for us and I had lost my mobility. So I was saying that surely that demonstrates exceptional circumstances if I can no longer walk around anymore.

But because they wouldn't define what "exceptional circumstances" meant, they would say not good enough and during that time they outright refused me anyway even though I had sent them the medical letters from the haemophilia unit, because what would happen it would be sent directly by the unit because it had to be written and signed by the consultant by that time. And they sent it by email to the Macfarlane Trust and the Macfarlane Trust said, "Yes, you have apparently medical supporting letters but you can't have the grant because you won't give us your outgoings".

Now, we would get grants for years having only ever given them our income to prove our income, which I always did. But suddenly they introduced a rule where they wanted your outgoings as well and they'd never -- because they'd never needed it, I refused to accept that they actually needed that information to grant a grant. They had the medical information, which is what I was saying. I am in medical need of this equipment and you have medical proof that I am in medical need of this equipment. You don't need to know any more. And I was saying that because I don't believe it's acceptable for me to be means tested out of support from a medical disaster charity.

Q. Your application in relation to the mobility scooter went back and forth.

A. I sent it back to them four times at that time.

Q. And they still said no and eventually you got so desperate that you funded the purchase of the mobility scooter yourself?

A. I actually had to buy it by the second time of asking because, regardless of the Trust, I am in medical need of this equipment. That's got nothing to do with whether they will pay it and, with all the grants, it's the case that we as victims can't wait three months for them to make up their mind if we deserve it

or if we need it. We need it for medical reasons and we've got medical letters telling us, telling the hospitals, telling them that we medically need it. So what happens in reality is we have to buy this equipment and we have to start using it whether they've made their mind up or not.

But their response to that was always, "Well, you've purchased it now. That makes it retrospective, so we're not paying for it now anyway".

Q. You applied again for a mobility scooter grant three years later in 2018 to EIBSS because you wanted a machine that you could fold away and put in the car?

A. Yes. So after the fourth time of asking through the MFT, I gave up on that. I'd been trying to get it from them for something like two and a half years and then it was all changed over to the EIBSS. I had given up by that point. I'd bought it anyway, the one I was able to use. I bought a larger machine because I needed to be able to get from my house to places and we'd always had a car that could take a larger machine at that point. But that then became a new series of problems. My actual machine that I got stopped being useable for certain scenarios.

What essentially happened is my wife took ill and I had to look after her in the hospital and I was

unable to get the scooter I had into any car, because I can't drive, to get to her. Although our car could fit it, I can't drive. So I needed a travel option to be able to both look after my wife but at the same time look after myself.

Essentially, I asked them because the EIBSS once more said, "We've got a new set of grants that are available again including mobility equipment", so I said, "Okay, then you're doing grants again. I'm going to ask you for what I've now experienced that I need" because I injured myself quite badly trying to look after my wife.

I applied to them and sent again medical supportive letters. Again, the unit is, although overworked being asked for these letters all the time, they fully supported it because they saw the mess I got myself into. And I was essentially told, "You're a haemophiliac and because you're a haemophiliac, that's why you need it; so you can't have it because it's nothing to do with your HIV status". I was banned from accessing disability grants because I was a haemophiliac, despite the whole reason they were set up was supposed to be to support us haemophiliacs that had been infected.

So I was furious. So every time I tried,

whether it was with the Macfarlane Trust, around this scooter that had -- I had a lot of need for it. The reason it mattered so much to me is it's the one grant where I had exceptional need in a life-changing problem that I needed this equipment and I had absolutely everybody vouching for me that I needed it and it was the only thing I could do, and yet by being banned from access for a multitude of reasons but the most insulting one is because I'm a haemophiliac.

They said in the new scheme they'd set up that you have to prove that it's related to your HIV status or your hep C status or the treatment of those two illnesses.

Q. Ultimately, you were able to satisfy that more --

A. They were still wrong because what actually happened to me is when I had the cancer, while I was doing the chemo I had to have lumbar puncture chemotherapy injected into my spine and then the third time they did my lumbar punctures it went kind of badly and they had to attempt it seven times, and it's that that's led to me having a lot of trouble with my back that finally put me in a position, after years of bleeding from that damaged location, which was directly associated with my cancer, which was related to the viruses that led to me needing the scooter in the first place.

So I basically had to send a 19-page complaint explaining to them that haemophilia for a start does not cause damage, it is the effect of an injury that took place because of a cause of something else, whether it's an accident or whether it's a fall or whether it's a medical procedure (such as it was in my case), wherever the locations are, haemophilia is a consequence of that. I started having to explain that to them and then explain to them what really caused the damage which was the damage from the chemo after having the cancer, which over years has caused me loads of bleeding in what's become -- in haemophilia turns they call it "a weak point" in either one of your joints or a location in your body where you bleed from an awful lot and it's persistent.

So I had to explain that to them and eventually, because I schooled them, I actually got the scooter in the end. But it was like having -- I was at war with them for three and a half years just for one grant.

But that's not the only problem I had with these grants. During the time I was talking about, when I applied for the scooter the first time, I had four rejected all for the same reasons, because I wouldn't give them my outgoings, which I knew that they had no

right to base their grants, the decisions on because they had no right to that information in the first place. Neither did they have the ability to check anybody's financial status. So they couldn't base their decisions on it because anybody could just make them up.

Q. The two other particular issues you had with the application processes that I wanted to ask you about, firstly, was about your attempt to get the stage 2 payment, which took again a significant period of time and you ultimately got it from EIBSS not having managed to get it through Skipton.

A. So when Skipton first was introduced -- I believe that was around 2005 -- and at that time I understand everybody that had been infected with hep C was put through with the Macfarlane Trust liaising with the hospitals about all the patients they knew about and as it was set up, we were all put through it and our medical records were checked and then, in my case, I was put on stage 1 at that time. At that time, the stage 1 payment was only a one-off payment, which they gave to me and then I essentially didn't hear anything else about it for a long time.

So I was considered to be on stage 1 until 2018 because they didn't know any different. In 2018 --

what had happened previously, sorry, in 2016 they added a stage 1 monthly payment which was low, it was like £3,000 annually but it was something, and I was put on the stage 1 payment.

However, in 2018 I received a letter which was about what they were calling a special category mechanism letter which explained that they were adding new illnesses to the qualifying criteria for stage 2 for the Skipton payments. In that letter that wasn't associated to the new illnesses they added, it said anybody that had suffered a B cell non-Hodgkins lymphoma will already be on stage 2.

When I read that, obviously I've said "but I'm not" and I immediately took that to the hospital and asked them, "Am I reading that correctly? Is that what that says?" and they said they read it the same way I did. So I had to call them up and find out how to apply for stage 2 because I'd suffered the non-Hodgkins lymphoma.

I then went back through the paperwork I did have from the original explanation of what Skipton was from 2005 (which I keep records of everything), also saw that I had no information about non-Hodgkins lymphoma now qualifying but they told me when I asked them that that was added in 2011, and they said that

coincided with the stage 2 payments becoming monthly payments.

So basically I had to reapply to the Skipton scheme to try to get put on the stage 2 payments. I had all my medical letters arranged by the hospital again, using the notes from when I was treated for the cancer in 2005/6. They sent that to The Skipton Fund and they said, "Ah, we see you do actually qualify for Skipton stage 2 and that will mean that you'll receive the one-off payment for being on stage 2" which was a £50,000 one-off payment "and that means you also qualify for the monthly payments for stage 2" which is much higher.

I believe that's the same payment as for HIV under the new scheme. I think that's 15,000 per year. So they said, "So you do qualify for that and you have -- we can see you've qualified for it -- well, it will be since 2005/6 when you suffered the cancer but the actual payments, the monthly payments, weren't introduced until 2011 so we can only do that from then".

However, they said, "Actually, we know you qualified from then but we're only going to pay you from 2018 onwards from when you applied because that's the way it works. We can't back pay you". So this meant to me a difference of I think it was £94,000 that I would have gotten from 2011 because they'd explained how long I would have received the payments for, but they said they're not paying it. They won't back pay it.

So I had to again go back to the earliest paperwork I had where it said that I could force them to have it reviewed in a court, a judicial review I think it was called of the decision, and it wasn't until I actually threatened to take them to court about this decision -- they said I qualified and they themselves had said I'd qualified since 2006 but they weren't going to back pay me to the 2011 when they told me the payments I should have been receiving had started from.

Q. And your statement explains that it was once you'd threatened to take them to court, you say, you got the letter that said that they would make the back payment to 2011?

A. I already had received -- once I'd qualified they sent me a letter that said that I did qualify from the period I explained, when I had the cancer, but they would only pay me from 2018 onwards in the first letter they sent me, and it was that that I challenged and I went back to them and told them, "That can't be

right. You've already qualified me from that period. You can't disqualify me for a period you yourselves have just qualified me for. You're telling me I was entitled to it from that point, so you can't take it away from me".

And I said that I wanted them to do this court review of my application because it was unfair, and it wasn't until I actually threatened to take them to court that they suddenly sent me another letter saying, "Actually, we will back pay it and we'll back pay it all back to 2011 like you are correct that you were owed".

So again, you don't -- it's like you can never get what you're supposed to be entitled to until you reach such a point that you're willing to take them to court to get it, and in that case I went that far because it was an extraordinary amount of money. So if I hadn't challenged them about that, I wouldn't have received it. If I'd just swallowed that I'd would have lost £94,000 and I'm sure there's many others who haven't known or who haven't had the old paperwork that established that you had the right to challenge them who they've told the same thing to.

I know that there are others who've tried to get the same things I have, such as the scooter, and that

was refused to those people as well. But because I fight them about things, I've eventually got through to them. But in that case, literally having to threaten to take them to court and then all of a sudden they decide, "Actually, you were always entitled to it, we were just trying to stop you getting it", it's absurd and it's obstructive and every element of the support systems is designed to stop you getting access rather than to support you. And I've experienced it over and over again.

Q. Mr AI, those are the questions I had for you. Is there anything else you would like to add?

A. Okay. One of the things I do need to say, it does relate to the potential consequences of the Inquiry itself.

It's pretty much been established that the Government keeps saying that it doesn't really want to pay out compensation. So I just want to put it on record that the Government seems to have a financial incentive not to pay out to us because their current situation in all the schemes is if we die, the way they've written the stipulations the payouts stop. So essential it's better for them if they wait for us to die.

That can't be allowed to continue. If there is

going to be any kind of whether you call it compensation or whether you don't call it compensation and they just raise the support payments, they have to make -- someone has to make it so that they're not allowed to only deliver them to the people that are still alive because, while they only have to pay out to people who are still alive, they can always keep refusing to pay it hoping that we'll die off so that they can save money. It has to be paid out in the names of the victims that have died as well, to the next of kin of those victims and the families that were also immensely damaged. I know their deed said in the Macfarlane Trust's deed that those people were supposed to be being supported every bit as much as we were as primary infected (in my case, kids) but infected haemophiliacs.

Someone needs to clarify that it's not okay for you only to support the ones that are still alive because when the victims have died, their families are devastated, they are going through financial hardship as well as the grief but the Government is saying, We don't need to support them anymore, that person died, cross-them off the list, their life doesn't matter. The fact that they were killed doesn't matter. To hell with them.

That can't be allowed to carry on. So whatever is done must include widows -- there's a major problem around where there were parents because they didn't necessarily call them widows, so parents weren't really thought of within the schemes in a way. There were some payments that some widows could get access to through the MFT, but they were minuscule, but there were no categories for parents, even though many of us were children when we were infected and when we died when we were young, they will always be classed as your next of kin, and yet there was no category to help them.

So whatever happens in the compensation system, it has to include the families of those that have died in the name of the person who was infected and who has died, because otherwise the Government still has a financial incentive not to pay out because it's just waiting for us to die off to reduce how much it costs. It's just not right.

Q. Thank you. Sir.

SIR BRIAN LANGSTAFF: Mr AI, during the course of your evidence you said how you described yourself to yourself as a broken, diseased thing. Let me tell you I do not see you that way. I rather see somebody who, despite having the fears that you have, despite never

coming out of your house except to go to particular events for a short time, and despite having the fears of anonymity you have, have been prepared to come here for the length of time that you have to give us the full value of your experiences and thoughts which you have, despite your saying that you have no social skills, mainly about other people and how things might be improved for them, and for that and for what you have told us, I'm very grateful.

A. Thank you as well.

SIR BRIAN LANGSTAFF: Tomorrow?

MS RICHARDS: Sir, tomorrow we hear in the morning from Susan Delglyn and Tara Allen and then from Janice Whitehorn-Cox and then we have two anonymous witnesses.

SIR BRIAN LANGSTAFF: We start at 10.

MS RICHARDS: Yes.

SIR BRIAN LANGSTAFF: So tomorrow at that stage. In relation to tomorrow, as you leave you may find that there is a leaflet of information which has been handed out. Please read it and take note if you are intending to be here tomorrow. Thank you very much.

(4.30 pm)

(Adjourned until 10.00 am the following day)

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