Witness Name: Martin Beard
Statement No.: WITN0012010
Exhibits: WITN0012011-021

Dated: 6/12/2019

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF MARTIN BEARD

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 6 November 2019.

I, Martin Beard, will say as follows: -

Section 1. Introduction

1. I make this statement in addition to my statement of 2 May 2019 (WITN0012001) and for the sole purpose of exhibiting documents of relevance which were not included with my first written statement. I gave oral evidence on 12 June 2019 at the Leeds hearing.

2. Counsel to the Inquiry has requested a second witness statement to exhibit the relevant medical records in relation to the withholding of information regarding my Human Immunodeficiency Virus (HIV) diagnosis, my hepatitis B (HBV) status, and my hepatitis C (HCV) diagnosis.

3. I can confirm that I am not legal represented. I do not wish any anonymity, because I want my story to be heard.

4. I am aware that there is a right to reply for criticised individuals and organisations in this statement.

Section 2: Background

5. I have provided my medical records obtained by Lieff Cabraser Heimann & Bernstein (LCHB) in contemplation of a class action against pharmaceutical companies in the United States. These records were not available to me at the time of writing my first statement, therefore this statement provides additional information to the Inquiry.

6. I was originally represented by Anderson Eden solicitors in Preston, they were the ones who I sent all the medical records to around 2004. I think that was organised through the Haemophilia Society. I don't remember the details very clearly, it's all just lost in the mists of time. I can't remember why the action moved to the United States. We did regularly receive letters keeping us informed of what was happening in the USA.

7. Anderson Eden forwarded all my records on to LCHB in contemplation of legal proceedings in America with a large pharmaceutical company. But, it all ground to a halt in the USA because the pharmaceutical company had the money to fight it. My middle brother and I went on holiday to America around October 2004 and LCHB said they would like to meet me, so we met them in San Francisco. We had a meeting and just discussed a few bits and bobs really. It was really just about how I found out about the HIV. I don't think there was anyone taking any notes.

8. I suddenly got these letters from Irwin Mitchell saying there was a settlement on offer. They offered me just over £22,000. Irwin Mitchell recommended that the other claimants and I place the money from the pay-out into a trust fund so we didn't get our benefits stopped or anything. I was on Income Support, so I agreed to the trust fund, because I didn't want the Department for Social Security coming after it but it cost us £750 each to set these trusts up. I think after ten years I've regained the £750 it cost me in interest. I can draw the money out whenever I want. But I've got to have my mum's signature to get at it to stop me having a mad moment and drawing it all.

9. When I received the £22,000 I felt I had been bought out on the cheap basically. It did stick in my throat because it's awful when you consider how many billions these pharmaceutical companies made, and that they had put money aside in advance to fight these claims because they knew the claims were coming. What they've paid was a drop in the ocean. But, I felt I had no alternative, it was a case of you either take that or you have nothing.

10. There wasn't a clause saying I couldn't pursue any other action if I took the pay-out in 2010. Obviously, I along with a lot of other people thought, "*God, £22,000 for what's happened to us, it's not a lot,*" but it didn't look like we'd receive any further payments for the pharmaceutical companies. Everything seemed to be such a struggle fighting a case 3,000 miles away. I often look back to the settlement in the early 1990's from the UK government – a lot of people went out and blew it because we thought we didn't have long to live anyway. There was a letter when I went into the hospital for a knee operation, saying I would only live for ten years. I had £10,000 left over from the UK government, that I used as a deposit to buy my house.

Section 3. Documents relating to HIV status

WITN0012011:

11. WITN0012011 is a nursing record from North Staffordshire Royal Infirmary dated 18 December 1987 which states in an entry at 4pm, *'Patient does not know he is HIV positive. To start factor VIII tonight.'* It was signed off by Dr GRO-D Registrar for Haematology. I was informed of my HIV diagnosis on 1 September 1986 by Dr GRO-D at the Staffordshire North Infirmary. This medical record was from the same hospital where I had been told about the HIV a year earlier. Something hadn't filtered down the system. That just seems barmy to me.

12. I talked about this at the hearings in Leeds. This record is from the time I was treated like a leper. I was put in a side room, the medical staff came in in full body hazardous materials suits even just to deliver my meals, and I had to make my Factor VIII up myself. I didn't ask why they were treating me like that, I would have been 18 years old, I was very quiet, I didn't speak up for myself. Fifteen months after I was told about the HIV my medical records were still being marked up saying, I wasn't aware. I can't think of any reason for this, it doesn't make any sense. Why would my consultant tell me on the first day I went to that hospital, and then the rest of the care team clearly still think I was unaware of it months later? The crazy thing about it is that Dr GRO-D was the top man there, I could almost understand the confusion if a junior doctor had told me.

WITN0012012:

13. WITN0012012 is a letter from Dr GRO-D addressed 'to whom it may concern' dated 29 March 1988, in which Dr GRO-D states that he has not tested Mr Beard for HIV

antibody since 1986 as he did not deem it clinically necessary. The test he's referring to is one of the last ones I had at Birmingham Children's Hospital. I mean I was under Royal Stoke University Hospital from September 1986 to about December 1987 when I effectively discharged myself. Apart from the first day when Dr GRO-D told me I was HIV positive, I don't remember HIV coming up in any conversations. None of the staff discussed HIV with me at all. His attitude on that first day was, well you've got two years to live and we'll look after you until then.

14. Dr GRO-D, I didn't really know the man because he only treated me for 12 months, but he had no compassion and on first meeting him I thought he was a totally ignorant of any feelings or compassion towards my predicament. I just thought, I've got to get out of here because psychologically I'm going to go downhill here because the whole place was depressing and they were treating me like a leper. They didn't tell me they were testing me for HIV in 1986. When Dr GRO-D says he must confess he hasn't deemed it clinically necessary, it just sums up to me his feeling was '*what's the point, he's not got long*', '*why bother?*'.

WITN0012013:

15. WITN0012013 is an inpatient medical record for an ingrown toenail from the John Warin Ward in the Churchill Hospital, Oxford dated 1 May 2001 which notes a history of HIV since 1983 due to a blood transfusion. It must have been 1 May 2001 because Dr Chris Conlon was the HIV consultant at the John Radcliffe Hospital in Oxford and I wasn't under his care until 1994. The records are signed by 'Mitchell', but the only Mitchell I knew was at the Royal Derby Hospital which was the hospital I was under before this treatment at Oxford. I think it was July that year I went to America, before that I was admitted for an ingrown toenail to Oxford. I did ask Dr Conlon once whether he had a rough idea of when I had been infected and he said in his opinion it would probably be the early 1980's.

16. I don't really have any thoughts on my HIV infection just that I was 14 and mixing with all those other kids and getting cuts, it just scares me the fact that I've had it so long and all that time I didn't know about it and potentially people were at risk. I remember this admission because while I was there I got approached by a doctor called Tim Peto for a medical trial of Interleukin-2 to stimulate my immune system. I came home and I started this Interleukin-2 trial, there were a hell of a lot of side effects but the plus side was that my CD4 count went from 450 to 1300.

WITN0012014:

17. WITN0012014 is a hospital admission sheet from the John Warin Ward at the Churchill Hospital, Oxford dated 7 December 2001, which states I had been infected with HIV for 18 years or more, which makes the year I was infected 1983. Obviously other patients who've been under Oxford longer than me will have other opinions, but I think my treatment from them has been A1. They've always treated me with dignity and openness and I've never had a problem with them. I've been a bit disappointed about doctors I was happy with attracting criticism from other people during the Inquiry. Dr Charles Rizza to me was superb, Dr Frank Hill was always good to me but let me down at the end. And that just disappointed me. But, with regard to Oxford I have no complaints.

WITN0012002:

18. WITN0012002 is a letter from Dr V E Mitchell at the Leicester Royal Infirmary to Dr D Perry of Birmingham Children's Hospital dated 11 October 1985. Dr Mitchell states, '*We know that he is HTLV 3 antibody positive but is not aware of this and that you do not wish this to be divulged to him. We shall make every effort to comply with your wishes.*' This was the first document that struck me when I first got my medical records. It's staggering, it really is. It doesn't matter how many times I look at it. Every time I have looked at this since I discovered it in 2004 it still just staggers me how the doctors, Mitchell and Perry, can be so nonchalant. I'm angry.

19. I'm so frustrated because I've never been given the chance to have it out with these people face-to-face and ask them why, what are they trying to achieve? If they were here today I would ask them, "*What benefit is there from me not being told? Why would you put other lives at risk?*" And for me that is the key word. Why? It's almost like they've forgotten everything they went into the profession for. It just shows such blatant disregard for patient welfare.

20. One thing that disappointed me, everywhere I've ever been, every hospital I've ever been to, GP's I've been treated by, whenever we've left to go to a new hospital or clinic we've always bought the doctors treating me a gift to say thank you for what they've done for me. When I left Birmingham Children's Hospital, we bought Dr Frank Hill a gift. We showed that appreciation and he didn't even have the common courtesy to share vital information with me about my HIV status and that was disappointing to say the least.

21. At the oral hearings, Jenni (Counsel to the Inquiry) brought the letter out (WITN0012002) and asked me my opinion on it and when it was that I first saw it. I can't remember if it was 2004 or 2006, basically, it was when I got all my records back from the hospital. I said I was stunned at the lack of respect for me and the blatant disregard for people's lives because they were putting so many people at risk. We even talked about the onsite nurse at the Leicester training centre where I was working because, to my knowledge, she wasn't aware of my HIV infection. If I had cuts or things she would have been treating me. The doctors knew but didn't share it with me or with any external medics. That's one of the things that shocked me. She'd be looking after lots of other people at the centre too. The things I was doing were high risk, riveting and sheet metal work, so I was quite likely to need emergency medical treatment. The sheer blatant disregard for human life was quite staggering really.

WITN0012015:

22. WITN0012015 is a letter from Dr Hill to Dr Mitchell dated 18 October 1985 stating, *'As far as his HTLV-III antibody status is concerned my attitude certainly is changing towards informing the patients … I am now firmly of the opinion that they have to face up to this reality and their children have to be also involved in discussions and certainly most of the teenagers have now been told, but I had not had the opportunity recently with Martin to do* so.' I would have been 16 years old, I wouldn't have been 17 years old until January 1986, when this letter was written. I'm most shocked when he says they have got to face up to the reality and that children had to be involved, but he'd not had a chance to speak to me. But we had telephones, he could have made the effort, or asked me to make the journey 35 minutes up the road, there can be no justification for not informing me earlier.

23. This is another thing that disappoints me, I'm almost being fobbed off after 16 years of him treating me. **GRO-A** **GRO-A**. It shouldn't have even got to that point, they should have been informing people straight away especially at that time they're thinking people have only two years left and people want to enjoy the last years left to them and it's like that life is being stolen away from them. It's almost like he's passing the buck, I was told about the HIV infection in 1986 at a different hospital by a different doctor.

WITN0012016:

24. WITN0012016 is a letter from Dr Hill to Martin Beard dated 12 September 1989 in response to a request from Martin regarding when his HIV status became known to medical professionals. Dr Hill writes *"As I am sure you are aware, testing for HIV antibodies did not become available until 1985. ... we managed to get one of the laboratories able to do the tests to actually look at stored samples we had. The earliest sample that we had stored on yourself was from 1983 and you were antibody positive during that year for HIV. Subsequent to that, we tested you on a sample taken on the 23rd April 1986 and this confirmed the previous positive test."* What struck me with this is I was 20 years old when this letter was written and it says "*as I'm sure you're aware*", why would I be aware of that?

25. I sent the letter asking for information because basically after I'd been told about the HIV in 1986 by a total stranger, I wanted confirmation. I wrote to Dr Hill asking for information quite a long time before his reply. By his own admission there was quite a delay in replying. It would probably have been 1988 I wrote to him and the reply only came in 1989. These doctors don't move fast. Dr Hill was very, very slow in responding to what I consider to be a very serious matter.

26. I was not aware they had stored samples and I was not aware they were doing any tests. I don't recall giving any consent for the storage of the samples. Dr Hill gave no apology in the letter, I mean, something simple like "*I'm sorry you had to find out the way you did*" or, "*I apologise for not discussing this matter with you*", would have been enough. Clearly, he was trying to dodge responsibility as much as he could. I just feel disappointed at being let down again by a consultant that I had trusted.

27. The first sample was from 1983, that's six years before this letter. I am sure it wouldn't just be mine they were storing, they'd be storing others. I'd like to know why were they storing it? I'd like to know why they were storing samples that were still viable for testing. How many were they storing? I don't know how many haemophiliacs were under Birmingham at that point, but 1,250 of us were infected, and I know Oxford had the most patients, but Birmingham would certainly have had a few. That's scary what they might be using them for. It makes me shudder.

WITN0012017:

28. WITN0012017 is a progress note from Birmingham Children's Hospital from April 1986 which states, '*Dr Hill contacted - does not know if patient is aware of HTLV III status*'. This just shows poor communication all down the line. It's, I mean, this is just nuts, all

patients should have been made aware by this point. This is just crazy. I mean, if the hospital had only done one test, you could understand that they might not be sure and might not want to tell someone and they'd want confirmation. But, looking at how Dr Hill was behaving and how Dr GRO-D behaved at North Staffs by not informing the rest of the staff, some of these doctors appear to be behaving as they like, on their own, and not in the patient's best interests.

WITN0012018:

29. WITN0012018 is a progress note undated but before 1 September 1986 which states, '*does not know HTLV status / neither does mother*'. This makes me think, how many people knew before me? There's another different doctor's signature on this one. It's the same problem again, other people are being made aware of my condition and I'm not. It's just such a lack of respect, and poor communication, and I have the right to know. And doctors back then, they really did think they were God. You can only make out occasional words in these notes but maybe trainee doctors are trained to read this kind of squiggle. When the notes are this badly written things are going to get lost in translation, surely?

Section 4. Documents relating to Hepatitis B and Hepatitis C

WITN0012019:

30. WITN0012019 is a haemophilia cumulative report sheet noting that Martin Beard's first positive test for hepatitis C was on 10 January 1991 and was confirmed on 2 May 1991. If this was 1991 this would have been at Derby, and I wasn't made aware of anything to do with hepatitis until 1994. I was told at a different hospital. The first positive one is 10 January 1991, my birthday actually. I didn't know I was being tested.

31. The only thing I remember about being under Derby and going every four months for a blood test to check HIV and CD4 count. They were testing me, I was unaware and I was carrying not one but two deadly diseases that potentially were a threat to other people. Especially when you look at the date, I was 21 and I could have been sexually active. Why? Why keep it a secret? If I had infected somebody then I'd have to live with that and the hospital gets to just walk away. It is so wrong.

32. Initially my treatment under Derby I was quite happy with, but things started to wane a bit when they wanted to give me a knee replacement in 1991 and that's when I asked for a transfer to the John Radcliffe Hospital at Oxford but I remained under Derby for

my clinics until 1991. I was told I was hepatitis C positive by Dr Chris Conlon in 1994 and that's the first I had heard about hepatitis at all. I had a referral to Oxford regarding my knee problem in 1992 and went in five months later for an operation on my knee. I was on Fluconazole and Sceptrin to try to stop things like cryptosporidium infection (Cryptosporidiosis is caused by cryptosporidium parasites living in the intestine wall. In people with efficient immune systems, a cryptosporidium infection produces a bout of watery diarrhoea which usually resolves within a week or two. For those with compromised immune systems, a cryptosporidium infection can become life-threatening without proper treatment).

WITN0012020:

33. WITN0012020 is a letter from Judith Oakley (Senior Registrar in Haematology, Birmingham Children's Hospital) to Dr Luft dated 9 July 1982 stating, "*When he was here blood was taken for an inhibitor screen to Factor VIII, liver function tests and hepatitis status. The last test for hepatitis showed that he has antibody to hepatitis B.*" Dr Luft was my GP at the time, one of the greatest GP's you could ever have, he was fantastic. If I think back to one of the original documents I saw from the Lister Institute dated 1979 in which Birmingham were asking for bottles of Factor VIII, the Lister Institute replied and said they could have some but that the available bottles had tested positive for hepatitis. Even though I understand that the UK was struggling to be self-sufficient in blood products at the time so they needed to be as efficient as possible, they clearly knew the product had a problem and they were still willing to distribute it.

34. The hepatitis is there at the forefront again and all the doctors who treated me clearly know that something was behaving oddly. At this time, the medical profession didn't know about the HIV virus but they were clearly looking for something, why else do these tests? When I think about this, I try to think of myself as a test subject because that is all I am to the doctors looking at my blood. The doctors looking at my blood back then were probably getting all excited because there's lots of things happening in my blood but I'm a human being not a test sample. To medics it's exciting. I've spoken to the doctors at Oxford these days and they talk about the 1980's as an interesting time. I wouldn't say it was interesting, but that's how doctors think.

35. The doctors treating me clearly knew there was a problem. Back then I don't think there was any treatment for hepatitis. But that's not the bloody point, hepatitis and liver function are directly linked to life style factors and you should be made aware, so that you can do everything you can. I don't know what advice a 13 year old boy could have

been given, but by 21 I was drinking and I still had no idea. They just want to keep everything away from you until it's too late. You would assume that all these notes they're making, you'd assume that when you move from hospital to hospital these are read, reviewed, and fully understood then the doctors would know not to offer me a hepatitis B vaccine. But clearly, they're not reading them because I was offered a hepatitis B vaccine by Dr Conlon at Oxford in 1994.

WITN0012021:

36. WITN0012021 is a letter addressed 'to whom it may concern' at Heswall Handicapped Boys Camp in the Wirral area dated 24 July 1979 which states, *"Martin ... has no inhibitor to Factor VIII nor is he Australia antigen positive."* I always called it Heswall Boys Camp, I looked it up online and it is still going but it has grown massively. They arranged days out for us and mostly it was just to give my mum a break, I think. This comes back to my GP because my GP, Dr Luft, actually drove me up there. He just did it because he was a good person. I took Factor VIII with me. I'd have been ten years old then, I wasn't self-injecting, my mum started injecting me in about 1976 and I didn't start injecting myself until I was 11 years old. Dr J Martin at Liverpool is mentioned in the letter and I do recall having to go to a hospital in Liverpool once while I was at the camp. I must have had a bleed while I was there, and they took me in. I went to the camp at least twice, possibly three times. But I only went to a hospital in Liverpool once.

37. There were various lads at the camp with various disabilities. I may have been the only haemophiliac there. I remember having one constant friend we always saw there and he was in a wheelchair. I think it was run by a guy we called Waddy, he actually came to my house once. He was at least one of the people who ran it.

38. I think I heard about the camp through the Haemophilia Society. I had a good time there. I remember playing snooker a lot. It wasn't overly massive then, there'd probably only be about 30 lads there. I remember when we'd go out on day trips there would only be one coach so there was definitely less than a coach load of us. We'd go out to Southport, a military museum at Holyhead, Fleetwood. There were some activities that were a lot more risky than others like abseiling or rock climbing and I avoided those. But I enjoyed it. The only time my haemophilia was mentioned was when the other boys asked me what was wrong with me. The only discussion I had about my haemophilia with the organisers was basically just me being told to tell a member of staff if I had a bleed.

Section 5. Other Issues

39. Even after all these years I am just so disappointed at being excluded from my own medical information. My only saving grace is that I didn't become sexually active until after I was informed so I could be responsible. It disappoints me that Dr Frank Hill and a wider circle of medics knew about my HIV infection and wanted to keep it from me.

40. If lessons are learned and all this is better in the future then it's all worth it. It's too late for the people that are gone, and in a way, it's too late for me because I'm already infected. The doctors say I should live a normal life span, but if there's one HIV sufferer dying every four days then I just start thinking where am I in the list?

41. I have been interviewed for the BBC, Russia Today, and the Times. The local paper got in touch and I was nervous about that because the interview I did in 1987 didn't go well and I got a fair amount of abuse about it. But, the response from people around has been so much better, people would stop me and ask how I was, and check how I was doing.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed GRO-C

Dated 6/12/2019