

Witness Name: Derek Harrell

Statement No.: WITN0943001

Exhibits: WITN0943002-4

Dated: 16/03/2020

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF DEREK HARRELL

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 June 2019.

I, Derek Harrell, will say as follows: -

#### Section 1. Introduction

1. My name is Derek Harrell. My date of birth is GRO-C 1957 and my address is known to the Inquiry. I live with my wife who I have been married to for around 30 years and we have 2 adult children.
2. I intend to speak about my infection with Hepatitis C by blood transfusion. In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my family and our lives together.

#### Section 2. How Infected

3. I was infected with Hepatitis C by receiving a plasma transfusion after an operation I underwent in 1981.
4. I was born with an issue with the bone structure of my nose which meant that the bone on the right side of my nose was thicker than the bone on the left side. As a result of this, I suffered from sinusitis and pain. The sinusitis affected me every now and then and caused me a lot of pain at times.
5. In 1981, I planned to go scuba diving. I needed medical clearance from my Doctor to confirm that everything was ok and to allow me to dive. When I went to see my GP at the time, Doctor Coulthard, we discussed my sinusitis and the ongoing pain that I was experiencing.
6. I remember the Doctor commented to me that I needed to either 'kill it or cure it'. He suggested that I go for an operation to clear the bone in my nose in order to remedy the sinusitis and the pain.
7. I was admitted to Queen Mary's Hospital, Roehampton, on 17 August 1981 and I had the operation on my nose on 18 August 1981. The medical name of the procedure that was performed on my nose is called a 'combined septoplasty and rhinoplasty'. A confirmation of my admission to and discharge from Queen Mary's Hospital is labelled Exhibit **WITN0943002**.
8. The procedure was the first operation that I have ever had. The operation was under general anaesthetic so I was completely unconscious for all of the procedure.
9. The Doctors also offered to break and straighten my nose during the procedure, however I declined this offer as my view was that I was born with the nose that I had.

10. After the procedure was over, I remember being in recovery. When I came to, I was vomiting up black blood. The vomiting was constant. The nurse said to me words to the effect of "Is this the first operation you have ever had?" and I responded with "Yes...it's not your lucky day then".
11. I remember going through recovery and then going up to the ward. My mother phoned from home to see how I was. I am not completely certain whether my wife (who was my girlfriend at the time) was on the ward when I arrived there, but she did attend the hospital to visit me.
12. My mother attended the hospital the day after my operation and the ward nurse told her that they had to give me some plasma to stem the flow of blood from my nose, as blood was streaming from my nose. I assume that this is because the blood was not clotting enough.
13. I had also been given a saline drip and my nose had been 'stacked', which means that padding was put into my nose. Stacking the nose is a pretty standard thing to do with these kinds of operations. The bleeding from my nose lasted a while and the padding was removed from my nose around 5-6 days into my recovery.
14. The day after my surgery, when she attended the hospital, my mother asked the nurses why I was in surgery for so long, as I was in surgery 3 hours longer than I should have been. She had a lot of questions for the nurses as to why the operation took so long.
15. I remember my mother saying to me, 'when I rang the hospital you were still in surgery, and when I rang again you were still in surgery and I thought this was odd, something is going on, something was untoward'.
16. My mother told me that she was at home fretting when she was calling the hospital and I was still in surgery. My brother had died a few years before under similar circumstances, where he was in surgery for a long time and passed away, so when she found out that I was still in surgery she was very worried.

17. I was originally told that I would only be in hospital for 2-3 days for the procedure. However, I actually ended up being in hospital for around 8 days.
18. The doctors and nurses did not say anything more to me about the bleeding from my nose and the transfusion while I was in hospital.
19. The bleeding eventually stopped and I was discharged from hospital. I went home and that was it, I thought nothing of it. Looking back though, it seems like it was a botched kind of operation. Something had obviously gone wrong for me to have the plasma transfusion, to be in hospital that long and to be given a saline drip.
20. Later down the track, I spoke to my GP at the time, Doctor Middleton, and he said to me that the fact that I was in hospital for 8 days, and was on a saline drip for this kind of operation, was odd.
21. Thinking about it now, it's clear that the operation must have been botched, something must have gone wrong. I think that my medical records may have been destroyed because the surgeon may have had previous complaints against him. At the time however, I didn't think anything of it, it's only now, after the fact, that I have been thinking that this may have been the case.
22. My wife later wrote a statement to accompany my applications to the Skipton Fund and EIBBS, confirming that I was given blood plasma after my operation.
23. I was not given any information or advice about the risk of contracting any infections at the time of my transfusion because I was semiconscious when it was given. I was given one or more injections after the operation, but I didn't ask what the injections were for. I don't think they knew anything about it at that time and I was just grateful to have the operation.

24. I got the feeling that the operation didn't go well, because of how long I had to stay in hospital, however I didn't question this at the time, as I didn't think anything of it. I was just grateful for the NHS's work. All I know is that I went into the operation feeling fine and came out feeling very rough.
25. In 2001 I noticed that I wasn't feeling too well, I wasn't feeling too clever.
26. I remember one occasion where I realised I was not feeling normal, I was sitting at work. I work as a Project Manager.
27. At the time I had started a new job and we worked with a lot of spreadsheets and various other things, and the processes we were working with at the time were very high tech and innovative. I remember sitting there one day at work and thinking to myself, I just can't understand this, but I should have been able to.
28. I was having trouble trying to reason. Although I already knew how to do this particular kind of work, it was just not becoming clear to me and I just couldn't put my finger on it as to why.
29. I had been feeling like this for around 6 months, things just weren't clicking at work, and I thought that maybe it was just the new job that I had started, or maybe it was just me, maybe I just didn't get the job.
30. I had also been feeling very tired, however this was not surprising to me as I was working long hours at my job. I was commuting to Gatwick at the time for my work, so I didn't really bat an eyelid at feeling tired as I was working long hours and spending long hours on the commute.
31. It was just the fact that I couldn't suss things out at work that troubled me. I thought this was odd as I was usually quite a puzzle boy and I liked to figure things out.



32. I spoke to my wife and she said to me 'why don't you go to the doctors and have a word'. I went to my GP at the time, Doctor Middleton, and he said that he would need to take my bloods, which was done.
33. After my bloods were taken, Doctor Middleton said that we needed to discuss the results. He informed me that Hepatitis C had been detected in my bloods. I have blood test results from 5 December 2001 which confirm this. They are labelled Exhibit **WITN0943003**.
34. It did not even occur to me that I could have Hepatitis C. I was shocked. Doctor Middleton was a good Doctor and he gave me good advice and adequate information about the Hepatitis C and how to manage it.
35. After I received my blood test results, Doctor Middleton referred me to Southampton Hospital. They assessed the viral load and assessed whether treatment was needed. They determined that treatment was needed and they wrote to the NHS trust in West Sussex to request funding for the treatment.
36. I was shunted up the list for treatment because I also had cirrhosis of the liver. I had a biopsy on my liver at the time which is how I was diagnosed with cirrhosis. There was quite an extensive covering of the liver so they deemed treatment as necessary so it was done right away. I was treated with Interferon injections and Ribavirin tablets.
37. The doctors and nurses at Southampton Hospital also gave me adequate advice and information on Hepatitis C and how to manage it. Although my GP, Doctor Middleton, gave me adequate information and good advice about Hepatitis C, I feel that the doctors and nurses at Southampton Hospital were able to give me better advice.
38. The operation on my nose was the only operation I had ever had prior to being diagnosed with Hepatitis C, and was the only time I have ever received a blood transfusion in my life. The only other surgery I have had was surgery for a hernia which was post-2001. I only had a local

anaesthetic for this operation though and did not receive any kind of blood transfusion.

39. I have never had any tattoos or piercings and have never used any kind of intravenous drugs.

40. It is because of this that I know the only way I could have contracted the Hepatitis C would have been through the plasma transfusion I received after my nose operation at Queen Mary's Hospital.

### **Section 3. Other Infections**

41. As far as I am aware, I did not receive any other infection besides Hepatitis C.

### **Section 4. Consent**

42. I do not believe that I was ever treated or tested without my consent, without being given adequate or full information, or for the purposes of research.

### **Section 5. Impact**

#### **Physical and mental impact of Hepatitis C**

43. As I mentioned before, I was shocked to find out that I had contracted Hepatitis C. However, the infection is not something that I ever thought would get the better of me. I thought, I just have to get on with it, I wouldn't let it get the better of me. I thought I just have to get on with the treatment and do what I had to do to get through it.

44. The physical effects of Hepatitis C that I experienced were being constantly tired and I was not able to function properly at work. I was quite fit at the time that I was diagnosed with Hepatitis C. Before I started

my new job at Gatwick, I would train 3 to 4 times a week, would cycle to work and back in [GRO-C] and when I moved to [GRO-C] I was keeping quite fit too, however not as fit as I was in [GRO-C].

45. I didn't drink much, I would only have a couple of beers a week, but as I mentioned previously, I was working very long hours. Because of the nature of the game I was working 70 to 80 hours a week, excluding Saturdays and Sundays.

46. In addition to this, I had young children and spent a lot of time looking after them and taking them out on the weekends. Because of this, I didn't bat an eyelid at the tiredness I was experiencing. I thought that this was just part and parcel of being a young family, I didn't think that there may be something wrong with me.

47. It was only once I started getting the cloudiness at work, and that I was not able to understand tasks at work, that I went to the Doctor about my symptoms.

48. I responded well to my treatment with Interferon and Ribavirin. The infection cleared up within a few months after I commenced my treatment. However, I had developed cirrhosis which I still have today.

49. As I mentioned before, when I was first diagnosed with Hepatitis C, the doctors did a biopsy on my liver. It took them 4 tries to finally do the biopsy and when they did it they discovered that lung tissue was present. As I mentioned before, the biopsy was what revealed that I had cirrhosis of the liver. I have only ever had one biopsy since I contracted Hepatitis C and it was this one.

50. They also did a test where they vibrated my liver. They did this test a couple of times then stopped.

51. At present, I need to have an ultrasound every 6 months at Worthing Hospital to monitor my cirrhosis. The nurses have told me that there are



no lesions on my liver and that my cirrhosis is stable and it is not getting any worse.

### **Physical and mental impact of the treatment**

52. As I have already mentioned, I received treatment for the Hepatitis C quite quickly. I received the Interferon and Ribavirin around 2-3 months after I was referred to Southampton Hospital and the Hospital received the funding required. As I mentioned previously, the Hospital wrote to the NHS trust at West Sussex to get funding for the treatment. The funding was granted quickly. I feel that the Hospital were pretty efficient in getting me treatment quickly.
53. I was treated quite quickly because I had an enlarged spleen and cirrhosis of the liver, and there was quite an extensive covering of the liver with the cirrhosis, so urgent treatment was needed.
54. I underwent the treatment for 1 year. The treatment consisted of 1 Interferon injection per week which I administered to myself at home, and daily Ribavirin tablets. I was given the whole 'wack' of medication straight away, and I was started on the Interferon and Ribavirin together. I had to slow down the treatment at one point as my white cell count got too low.
55. The first Interferon injection was administered to me at the Southampton Hospital by one of the nurses. The nurse showed me how to administer the first injection into my lower leg. I then administered the subsequent injections to myself at home. My wife contemplated doing it but she has an aversion to needles.
56. I remember after I received the first injection at the Hospital, the nurse said to me, 'you need to get home as soon as you can, you can't drive, you need to get home quickly and lie down'. She told me that I would feel quite rough after receiving the injection.

57. I remember literally shaking for about an hour/ an hour and a half after receiving this first Interferon injection. It was quite scary and I was actually close to ringing up the nurse as I was scared about the shaking. I just lay down on the sofa when I got home and waited for the shaking to stop. I was surprised at the reaction at first, I wouldn't call it violent, but my wife was very worried and kept checking to see if I was ok.
58. The shaking only occurred after the first injection and after that the side effects were not as bad as what I initially experienced. With the subsequent Interferon injections, I experienced general flu like symptoms and generally just felt absolutely 'wacked'. I also experienced a lack of appetite and weight loss.
59. My whole body ached, everything ached constantly. It was like having a flu, except there was no nasal congestion. It was just a constant aching, but you kind of get used to it. When it got really bad I took paracetamol. I lost quite a bit of weight as I had lost my appetite. I went from about 13 stone to 11.5 stone.
60. Administering the injections to myself was difficult as I had to disappear off to a room in the house to do it as my kids were quite young at the time. I didn't tell my kids about the infection at the time, they didn't know what was going on. As far as I knew at the time, Hepatitis C was a killer and a lot of the success they were having with treatment was 50/50, so I thought you just have to get your head down and do it, you've just got to do it to recover.
61. I also suffered with depression around this time. I had a discussion with the nurses at Southampton Hospital. They asked me if I was feeling depressed and I told them words to the effect of that 'I wasn't jumping for joy exactly'.
62. I asked them if the feelings of depression were a side-effect of the treatment I was receiving and they confirmed that they were. They

offered me Prozac to treat the depression but I declined it as I did not want the medication if the depression was a side-effect of the hepatitis C treatment, and I was concerned that it would affect my work.

63. The nurses also said at the time that they could organise counselling for me, however I decided not to take the counselling. One of the nurses was absolutely magic, she knew exactly what you were feeling and what the circumstances were.

64. The nurses spoke about a lot of things regarding my mental well-being, but I said let's just do it, let's just crack on. I feel that they were trying to suss me out to see if I was a person that needed more help or support in that way, or if I just wanted to crack on with things.

65. The hepatitis C infection cleared up quite quickly after I began the treatment with the Interferon and Ribavirin. The virus cleared around 2-3 months after I commenced the treatment. Within that time my LV levels went right down and a viral check was done and nothing was present.

66. I asked one of the nurses at Southampton if this meant that I could stop the treatment and she said no, as there may be underlying points of my body where the infection had not been detected and cleared. For example, there may be little vessels where the infection could hide and could not be detected.

67. Another reason why the treatment was continued was because I had cirrhosis and an enlarged spleen, and I also think that it was because the drugs were quite new and they did not know what the outcome would be if they were stopped, for example, if the infection would come back.

68. I had heard of situations where the treatment was stopped and the virus had come back for some people. They said that I should continue on with the treatment as I had nothing to lose. As I mentioned before, I ended up continuing the treatment for the period of a year.

69. After the year of Interferon and Ribavirin treatment had ended, I was monitored every 6 months at Southampton Hospital by the nurses. I would attend the hospital and was given an ultrasound and had my bloods taken.

70. I was eventually transferred to Worthing Hospital which is closer to my home and monitored there. I received an ultrasound every 6 months at Worthing and I continue to be monitored this way, up until today. Today my cirrhosis is stable. One of the nurses told me that it is not as bad as it was and that it seems to be getting better.

71. The nurses say that at present there are no lesions on my liver and the cirrhosis has not got any worse. I do not really listen too closely when I got to the appointments, as long as everything is fine I just usually go and then walk out.

#### **Impact on Family Members**

72. My wife and I did not initially tell our kids about my infection and they did not know what was going on. As I mentioned above, I would disappear off to a room to administer the Interferon injections to myself.

73. We eventually had to tell the kids [GRO-C]. We just told them that I had an infection and that it would eventually clear, that life goes on. The kids seemed to know that I wasn't feeling too clever every now and then.

74. The hepatitis C diagnosis put strain on my relationship with my wife. It was tough on our relationship at first, even though she knew that I had not been with anyone else.

75. I remember having to separate my toothbrush from my kids' and my wife's toothbrushes to prevent the spread of the infection. I also had to separate my towels and everything else. I was basically segregated from the family unit until we knew what was going on, as initially we did not



know the level of my infection. If I cut myself I had to be very careful I didn't get blood anywhere. I felt like I was a bit of a leper in my own house.

76. I didn't want to cause any undue stress to my kids so I wanted to go about dealing with the infection without worrying them too much and told them everything would be fine.

### **Stigma**

77. I only told my wife, my boss at the time, and eventually my kids about my infection. I didn't tell my friends or anyone else because there was such a stigma with hepatitis C at the time and I didn't feel comfortable telling them.

78. I have only recently told my extended family about the infection.

79. There was always this thing, this assumption that if you had hepatitis you'd had sex outside of your marriage or you were a drug addict, because no one knew it was coming from a bad blood source.

80. When I initially found out and read about what hepatitis C was it was shock horror and I know that people in this world judge, and that's why I didn't tell anyone else.

81. I remember one occasion where I had a phone conversation with a woman who worked at Southampton Hospital. I can't remember exactly what the conversation was about. I think that I had called to ask about a date for some treatment.

82. She told me that I would have to wait and I asked if there was a length of time. I can't remember exactly what her response was but she was quite abrupt and her attitude was bad.



83. I got quite frustrated and responded with words to the effect of "this isn't my fault, I don't know why you are treating me as if I've done something wrong".
84. I believe that she was treating me like this because I had hepatitis C. I feel that her attitude toward me was bad and that her attitude was that I was lucky I was getting anything from the hospital. Thinking about it now, I see why her attitude toward me was like that as the majority of people believed at that time that you got hepatitis C through being a drug taker.
85. After this experience I thought, life is life and you deal with it as it comes to you.
86. I literally looked grey during my treatment and people started to ask if I was ok because I looked so grey. I told them that I was just having a few health problems. I could not tell them that my appearance was due to the infection and treatment as hepatitis C had such a stigma at the time.
87. I felt like a leper in my social life as well. My friends were backing away as I was losing a lot of weight and not looking well during my treatment. At this time my friends stopped coming around and I didn't encourage them to come around to my home.
88. My infection was not an issue for my family, but I kept it quiet with others because I got this niggly feeling that people don't believe you and think that you have got the infection through using drugs or sex outside of marriage. I did not want to be pre-judged and I knew that people would pre-judge me.

#### **Financial Impact**

89. My boss at the time was the only other person I told about my infection, besides my wife and kids. I had only been in my new job for about 6 months when I was diagnosed with Hepatitis C.

90. I told him about the diagnosis. I told him that I may have to bail out of the job because of it. He was brilliant, he was very understanding and told me not to do this. He said that the company would do whatever they could to accommodate me, such as working from home etc.

91. I very rarely took days off work as I wouldn't give in to the infection.

92. I feel as though the hepatitis affected me from a career point of view, as at the time I was looking at getting into project management and I was looking at possibly leaving my job in the future to get into a larger company.

93. Once I was infected with hepatitis, I felt like I no longer had the option to do this as if a prospective employer for a big company went through my medical records, that would be it. I feel like the infection stopped my career progression as I didn't feel as though I could work for a larger company.

94. I also feel that my lack of career progression may have been because I was so tired all the time due to the infection and the treatment.

95. So, I just stayed where I was as I knew the people there and they knew me, and if anyone had medical problems no one mentioned it.

96. There was discussion of me going for a higher position with the company, but I just felt so tired all of the time due to the infection and the treatment, so I didn't really bother.

#### **Section 6. Treatment/Care/Support**

97. I did not face any difficulties or obstacles in obtaining treatment, care and support in consequence of being infected with Hepatitis C.

98. I received the Interferon and Ribavirin treatment quite quickly after the hospital wrote to the NHS trust for funding. I received the treatment about

2-3 months after we got the funding and the funding was received quickly.

99. As I mentioned above, psychological support was made available to me by the nurses at Southampton Hospital, however I elected to decline that treatment.

100. The nurses at Southampton Hospital were amazing and if it was not for them I would not have got through my treatment, they were so good. There was a couple of instances where I was not able to contact Doctor Middleton and they got in contact with him and he came out right away.

101. If I ever needed to talk about anything, they knew what to say and they said the right things at the right time, they were magic.

102. I am very happy with the way that my care has been, and is currently being dealt with. As I mentioned above, my care has now been transferred from Southampton Hospital to Worthing Hospital, which is closer to my home. My care here consists of monitoring my condition every 6 months because I still have cirrhosis. When I was transferred to Worthing Hospital, one of the nurses there did all of the tests which were initially performed on me at Southampton Hospital again, they are very thorough.

## **Section 7. Financial Assistance**

103. I was aware of the existence of the Skipton Fund and of EIBSS. My cousin who is a Magistrate in London encouraged me to apply to the funds. She said that I would likely be entitled to financial assistance through the funds because of what happened to me.

104. My GP Doctor Middleton also encouraged me to make the applications. Doctor Middleton helped me prepare the forms for the Skipton Fund application.

105. I first made an application to the Skipton fund and then to EIBSS. Both of my applications were rejected as they said that I needed to supply my medical records which I could not do.

106. I tried to get a hold of my medical records from Queen Mary's Hospital in Roehampton, where I had my blood transfusion. I called the hospital and also sent them a letter to try to get my medical records. I rang the hospital on a couple of occasions and had a conversation with a woman from the hospital. I ultimately received a letter back from the hospital which stated that after an extensive search they could not find my medical records. This letter is labelled as Exhibit **WITN0943004**.

107. I could only get a couple of letters from my former GP and my current GP Doctor Middleton. Doctor Middleton could only give me one document about the actual operation on my nose. Doctor Middleton commented that given the operation I had, it was unusual that there were so few documents and that I should have had a bigger file.

108. After my Skipton fund application was rejected, one of the nurses at Worthing Hospital said that I should apply to EIBSS, and I said to her words to the effect of, "what is the point I don't have my medical records". She told me that the funds now recognised the fact that some people didn't have their medical records.

109. When I was denied financial assistance by both funds, I thought I won't bang my head against the wall any longer when it is clear that they have no intention of paying out.

## **Section 8. Other Issues**

110. It's one of those things, isn't it, in life you get thrown curveballs and you deal with it. When this was thrown at me it was devastating and I had to do a lot of soul searching and thinking. I remember driving my car to work one day and stopping and just having this outpouring of grief.

111. My way of coping was to always set targets or goals for myself and my family, for example, to get through the next 6 months, or to get my children through university.

112. I am annoyed that the NHS put out blood when it was infected, but it is what it is. I'm not the kind of person who will sit there and cry over spilt milk. I do feel let down that they knew there was this infected blood problem and they kept banging it out. At the time I thought that the NHS were there for me, not knowing that it was their fault in the first place.

113. I have learnt to live with the infection. It has impacted me, yes. It has impacted the way that I've looked at things and approached work but I've also found that you have to get on in this life.

**Statement of Truth**

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

Signed 

GRO-C
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Dated 16 / 03 / 2020