Witness Name: John Aubrey
Statement No.: WITN0071001
Exhibits: **Nil**
Dated: 12/02/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JOHN AUBREY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4th January 2019.

I, John Aubrey, will say as follows: -

Section 1. Introduction

1. My name is John Aubrey. My date of birth is GRO-C 1963 and my address is known to the Inquiry. I intend to speak about how I came to be infected with Hepatitis C (HCV). In particular, the nature of my illness, how the illness affected me, the treatment received and the impact that living with HCV had on my life.

Section 2. How Infected

2. I now know that I contracted Hepatitis C in November 1990 when I had a blood transfusion, though I did not learn of this until being diagnosed about 5 years later. At the time running up to the blood transfusion, I was living in Croydon and working as a manager at a branch of the off-licence, Threshers. I had been diagnosed with Ulcerative Colitis, I was given medication to combat this but it subsequently became apparent, that the doctor who gave the medication, had given me a double dose, in error or

incompetence, I do not know which. Either way, it appeared to have superficially cleared the cancer when I was tested by another doctor who then took me off the medication. A few months later the cancer came back with a vengeance.

3. The doctors then established that I had been 'double dosed'. I was losing a lot of blood, without realising it at that time. I came back to Wales for a friend's wedding and collapsed at the stag party. I was rushed to hospital by a neighbour. Two local GP's initially stated different reasons for my collapse, one said it was a water infection and the other stated it was a kidney infection. A third doctor, at the hospital, said it was anaemia and I was told that without intervention, that I had been about three weeks from dying, due to the rate of blood loss.
4. I was taken to the Bridgend General Hospital, which was an old hospital later demolished and replaced at a different location, by the Princess of Wales Hospital.
5. I was in hospital for a week during which time I had received a blood transfusion.
6. After the November transfusion, they operated and took my large intestine out. I was told not to work for 18 months but I went back too early, after 3 months. I was exhausted at the end of every day but I lasted a month before I went on the sick and took the full 18 months off. I went back to work far too early and well before the advice I had been given. I returned home to GRO-C. I had had four blood transfusions in total over a period of about 10 months.
7. I then went to work for as assistant manager at The High Tide inn, a large bar/entertainment venue in Porthcawl. I felt back on track at this point, but it obviously took effort to go back to a 40-60-hour week. After two years and feeling better, I returned to London. It would have been about 1992/93.
8. I worked for the Garfunkel's restaurant chain, at the Heathrow and Gatwick airport branches, as a duty manager. In 1994, I went to work for Ponti's, an Italian restaurant chain in their Marylebone branch, as a duty manager, both in the restaurant and outside catering for events and regular corporate clients.

9. In 1995, after being at Ponti's for about a year, I was contacted by my Mum. A letter had been received at home in GRO-C. It was obviously of potential concern, I don't remember if it was marked 'NHS' and/or urgent but I told my Mum to open it. The letter was from a doctor or specialist and stated that there were problems with my blood and I needed to contact them as soon as possible. It did not state what the problem was, only that 'there was a problem with the blood results from one of your transfusions'. The doctor gave his home phone number, he was the head of the haematology centre in Pontypridd at the time. I called the number and I was told that I had been given the third transfusion from a batch of contaminated blood. I went straight home to Wales, as my parents were panicking. They thought it might have been HIV, heavily in the news in that period. I remember however being told that I may have Hepatitis C and this was confirmed by a subsequent blood test.
10. The doctor explained that the 3rd transfusion that I received in November 1990, was tainted. He said that an imported batch of blood from America, specifically American prisons, was given to me. I was told it was an incurable disease and that I needed to go to the hospital to sort things out and to see what they could do for me. i.e. whether there was any medication.
11. Apparently, they had been looking for me for 5 years, and the doctor apologised that for the length of time it had taken to locate me but none of the medical establishments had my address. I find this astonishing, and nonsense, because my medical records were with the local GP, plus I was still under Neath General Hospital in relation to my Colitis issues. I was having six monthly check ups. I had had my large intestine removed and a 'pouch' fitted internally.
12. At this time, I was under Neath General Hospital, for the Colitis related monitoring, whilst St George's in London dealt with my HCV for about 6 months before I returned to Wales. During my time there I received no treatment as there was none, they checked my bloods and conducted liver function tests. St George's advised me not to go to a liver specialist as Hepatitis C was viral, but when I moved back to Wales, the only people at the hospital, were liver specialists. I never received or was offered any counselling or phycological support.

13. During this time, I didn't feel affected by the Hepatitis C, I assumed this was because the doctors said I did not have that much of it compared to other people, I was told I had a 'type 2 genome' but no one explained to me what this actually meant.
14. Over a period of time and looking back now, the symptoms became more apparent. I was lethargic and I was picking up more infections and colds than I had done in the past. At the time I was working long hours and it was as much as I could do to go to work. I could do little else. It was my work ethic and not wanting to let people down that kept me doing this. Looking back, it was definitely the Hepatitis C that was dragging me down.

Section 3. Other Infections

15. In relation to the HCV, I have not been otherwise infected.
16. My issues relating to the Colitis continued but were unconnected.

Section 4. Consent

17. I have always consented to medical treatments. I think I consented to the original blood transfusions – it was either that or I would not have survived. If I didn't consent, because of the situation and my condition at the specific time – I would have, it was critical but I most certainly did not consent being given blood, contaminated or otherwise from an American Prison.

Section 5. Impact

18. When I was first informed that I had Hepatitis C, I was told to contact past partners so that they could get checked out. This was a horrible and an extremely uncomfortable thing to have to do. I had recently become engaged to a GRO-C woman in London and when I told her, she promptly ended the relationship.
19. After the diagnosis, I was at a very low point in my life, with apparently no light at the end of a very long tunnel. There was no cure for the Hepatitis C. Everything was getting on top of me. I didn't know what was ultimately going to happen. My relationship had ended and any prospect of future relationships was thin to say the least. On top of that there was the stigma that I was carrying. It was an unclean desease associated with drug

addicts and prostitutes. I was suicidal. This culminated in me being pulled back from the track at New Bond Street Tube Station. I was moving close towards the edge of the platform when unknown to me, a work colleague was watching and intervened by putting his hands on my shoulders. He knew I had been going through some problems This was a turning point and the most serious manifestation of my suicidal thoughts, though they did continue to a lesser extent after that incident, which occurred in 1995.

20. I had told everybody I worked with, that I had Hepatitis C because I could accidentally cut myself at work and people needed to know. It didn't affect my relationship with my co-workers or my friends.

21. It definitely affected being able to meet someone to spend my life with and any such relationships were non-existent. I had to disclose I had Hepatitis C and I felt like a leper to people, again stigma. As soon as I mentioned it they were gone, they did not want to know me. I stopped trying at some point and immersed myself in my job.

22. My mum was not shy in telling people that I had Hepatitis C, so she told her friends. It did not affect my life in that sense, I live in a small community (in South Wales) and I have a lot of very supportive friends, they helped me through my colitis and they helped me through this. I think being around them and then sharing a flat with my best mate was for the best, he gave me a good shaking after he found out about the suicide attempt. As I say that was a turning point

23. I felt I had to explain why I got Hepatitis C, some people treated me as a leper, some people didn't. I have had people come up to me and say they didn't know I took drugs, or that they didn't know I was gay, because it was projected like that in society at that time. Even some people who weren't ignorant, and knew more about it, did not want to stick around.

24. I have two step-children, who are Lianne's (my partner) children. I have no children of my own biologically, I would have loved to have had my own children but even then, with colitis, I was told it would be difficult to have children. If I had found the right person earlier I would have wanted children, but I am 'Grandad' to two girls and they see me no differently. I got what I wanted in the form of Lianne's family.

25. At work and in life I had to be careful with every little thing I did. In the catering industry when I got cut, I dealt with it myself. One time I knocked myself out and hurt my head badly, I wanted to deal with it on my own but my boss insisted that she helped despite not wearing gloves. Anything at work that had my blood on it, was obviously disposed of straight away.
26. Working in the catering industry, although it didn't happen regularly, I did cut myself picking up broken glass etc. But I didn't let this stop me dealing with things, I would just ensure that I dealt with my cuts and the blood myself. I was never told that because I had Hepatitis C, this career was no longer for me. The management were largely understanding but didn't let anything get in the way of getting the job done.
27. I was always conscious that I would have problems getting another job because I would have had to disclose Hepatitis C and I don't think other employers would have had the same outlook as my current employers have had all along. They expect me to work even when ill but they never turned around and said I needed to leave because I was a danger. I progressed where I was because it felt safer, it may have impacted my ability to get a job elsewhere but I can't be certain as I never tried to move on.
28. When I went on a trip to America in 2004, I was on a round of treatment and had to take needles with me, the security personnel in Dublin stopped me. When I informed the female security officer of the reason for the syringes, she told me that her son had Hepatitis C. She was lovely and understood. I was fine getting it through security there and back. During the time away, my older brother administered the injections. I could never do them for myself.
29. In terms of information about Hepatitis C from the NHS, not much was given to me. I did read leaflets about Hepatitis C but these I picked up from the hospital while waiting for appointments, I wasn't given them.
30. I didn't have difficulty getting insurance, although for life insurance I had to pay a premium and I couldn't get critical illness cover. For the first two years when I bought my house, the insurance was double, but that will have been due to the colitis as well as Hepatitis C. For travel insurance I didn't struggle, although I expect it was a little more expensive.

31. In relation to the HCV, I underwent three lots of treatment in total, each time it was Interferon and Ribavirin but at varying dosages.

32. The first treatment was around 2001, I was 38. I moved from Neath General Hospital to University Hospital of Wales in Cardiff. I was asked if I wanted to go on the treatment for 6 months, this consisted of an injection alternately in each leg, 3 days a week at the local surgery, by a nurse, this was the Interferon. I was given two tablets once a day which was the Ribavirin. I don't know if it was a trial, I was not told it was. Although looking back, I believe the third round of treatment may have been, though I was never told this.

33. After the first round of treatment I did not feel very good but I did not know how I was supposed to feel as I was not told what to expect. The injections made my legs sore, I was tired and lethargic but that was about it. I was able to do the work. I also kept up the gym as I needed to keep myself fit and strong for the long hours at work.

34. During this time, I went through depression where I did not want to do anything other than what I had to do at work, but I put it down to a state of mind and I did not feel the Interferon intensified it. The suicidal thoughts had stopped, but I realised I needed a change and move back to GRO-C, luckily I was able to get work again at The High Tide, where I am to this day.

35. At the time moving back home did not feel like a good thing but looking back, it was. If not, I would not have met Lianne, my wife partner – we knew each other our whole lives really and I told her about the Hepatitis C the first time we went out together. She has stuck with me ever since.

36. Over the first period of 6 months, the treatment did not even touch the Hepatitis C and the results were the same as before. I continuously went back every 3 months to have more blood tests done. I was told the results of the blood tests at an appointment with the specialists at the University of Wales Hospital.

37. I felt deflated that the treatment had not worked, especially as the doctor had been so optimistic, because he said the HCV was not that prevalent in my system. I was devastated but there was nothing that I could do about it.

38. Before the next round of treatment, the symptoms became worse, though the level of HCV was apparently not and nothing was showing up on the

liver tests. I felt more lethargic and by this time I was having more colds, my immune system was getting lower.

39. I had a biopsy in 2004 before the second treatment, it didn't show damage to the liver at that time but the biopsy was painful to say the least, I had to remain conscious while they did it.

40. For the second treatment I was given a much stronger dose of Interferon, though this time it was one injection a month. The tablets were every day again. I had the injection appointment at the hospital so they could keep an eye on me, and a blood test was done after every injection. It was done on a Tuesday morning so I could go to work in the afternoon.

41. After the first lot, I collapsed at work on the day of the injection, my colleagues thought I was having a heart attack. My boss rushed me to the GP where they checked my blood pressure and put me on a heart monitor. I rang the hospital the following morning and explained the situation, they told me to go in.

42. I went in and explained to Tara, the nurse who dealt with my treatment. She cut down the dosage as it was too high, I assume she got in touch with the pharmaceutical company to explain what happened.

43. I received a call a couple of weeks later from the GP to go in as soon as possible to see the doctor as there was a problem with my blood results. After arguing with the receptionist in the local surgery, who would not give me an immediate slot, I had to contact Tara to explain the situation. She threatened to take them to the British Medical Association if the receptionist at Portway Surgery refused to give me an urgent appointment. Perhaps if the doctor, who was not my regular GP, had seen my full records he would have seen that I had Hepatitis C so he wouldn't have asked to see me with such urgency. Anyway, yet another unfortunate example associated to the HCV

44. This time during the second treatment, I felt a worse, more tired and I also now started to lose weight, I believe due to the treatment. I don't gain mass because of the 'pouch' so the two stone I lost, was weight I could not afford to shed. It stopped me from going to the gym because I was so tired. I was coming home after work, collapsing to sleep then getting up again for work. I felt I couldn't continue to do this but I refused to take off any time. I don't

like to take time off, I've had an operation in the morning and been back at the work in the evening, because I am dedicated but also in this industry the employers expect it.

45. The doctor put down the weight loss to the treatment and every time I went in he checked my weight. He told me to eat more, and to eat more often but with the 'pouch' there are certain things I cannot eat, plus I cannot bulk eat, so I need to eat little and often, which is difficult in the catering industry.

46. My sleep patterns were all over the place and I suffered stress, worrying whether the treatment was going to work and whether I was going to have to do this all the time. It was getting me down and I was getting more irritable with Lianne, which affected our relationship.

47. I was frustrated and couldn't put it down to anything in particular, apart from the treatment, I wasn't suicidal at this point but I was depressed. At work I was having more disciplinary type conversations with my bosses, mainlly to do with my attitude and how I dealt with customers. It was affecting my performance and my superiors had to speak to me regularly. I was offered anti-depressants by my GP but I turned them down. I did take them when I first found out about Hepatitis C but I was only on them for the first few months, they helped me sleep.

48. After 6 months on this second round of treatment, the tests confirmed that the Hepatitis C was still there. The specialists said it should have eradicated it and because it didn't, they wanted to call it a day with the treatment. With my negative outlook, it felt like it was 'just my luck' again.

49. After the second round I regained some weight but it remained up and down, I assume due to my system and the colitis. I knew I needed to remain strong in case anything happened with the colitis so I continued going to the gym.

50. I kept having tests done every 3 months and was told my health would degenerate over the years. After one blood test, Tara said that the pharmaceutical company could not understand why it had not cleared and said that they wanted me to go back on the treatment. I said not again. It was a stronger treatment and designed to treat strain 1 of HCV, I was given to understand, even though I had strain 2. However, Lianne and Tara persuaded me to go on it, about 18 months after the second round had finished.

51. The third treatment was around 2005/2006, it was one jab a week. I didn't collapse this time, I assume because my system was partly used to it, but it was more intense. A dietician prescribed me a supplement to keep my weight regulated as it had dropped rapidly, the supplements did work. The dieticians were there at every appointment to check my weight, usually around 78/79 kilograms.
52. The symptoms were worse, my sex life was non-existent, I was tired, more irritable and felt more depressed. I wanted to give up with it but my mum and Lianne said I had to carry on. I was not in a good place, there were times when I didn't visit Lianne because I was so tired, and I didn't have the energy to do things like go for a stroll with her. I only had energy to get to work and nothing else.
53. I carried on with the treatment and after 3 months showed a very slight clearing, I felt deflated as after all that, the drugs had done very little. However, after a further 3 months, the tests showed it had cleared.
54. My specialist's bedside manner was atrocious. After the final treatment (which completely cleared me of HCV), he gave me the 'third degree' and accused me of putting myself on the treatment when I should not have. The nurses and the pharmaceutical company had put me on the treatment. I didn't and still don't understand how I was put on the 3rd treatment without him – the specialist knowing about it.
55. It's hard to believe that he was not told anything about it because if so, he or someone was not doing his job properly, surely the specialist had to sign off on it. I was not told I had been on a trial but looking back I may well have been. If I had been told it was a trial, I probably would not have gone through with it. I did consent to this treatment (further discussed in section 4, Consent). Anyway, it had worked and that was all I was concerned about.
56. I was monitored for two years after 2006, having blood tests, to ensure it did not come back. Then I was discharged and I never had to go back for Hepatitis C.
57. My health improved, even though I think it's good in comparison to what it was, it is not what it should be, if I had not caught Hepatitis C. I have many sleepless nights, my immune system is not great, I regularly get colds. Also, I never used to suffer from being cold but now I do, my feet always feel like

ice. I still feel severe tiredness. My appetite is not the best. I have a lot of itchiness and I suffer from scratching a lot more, especially at night resulting in more lack of sleep. Erectile dysfunction is also part and parcel, I had this when on the treatment and it has not improved.

58. My eyesight had rapidly deteriorated. Although I am not sure whether this is due to older age or the treatment. Prior to my treatment, I had 20/20 vision. The rapidity of my loss of vision leads me to believe it is related to the treatment, plus it was listed as a side effect of the drugs.

59. I have problems with my bladder, which was a side effect of the treatment, and tests have shown the flow isn't right.

60. Although this is not listed as a side effect of the treatment, I have an enlarged prostate and I am being tested and monitored for prostate cancer.

Section 6. Treatment/Care/Support

61. Whilst I had Hepatitis C, I was the last in the day for any operations, but now I don't have it, it is no longer an issue. When I go to doctor's and dental appointments, I no longer have to declare that I have Hepatitis C. When I had HCV, I had to tell everyone and they had to do things differently. For any examination they had to be extra careful, for example, wearing double gloves. I have never been treated publicly as different by medical professionals for having Hepatitis C.

62. In reference to general treatment for Hepatitis C, the NHS has been good, if I had a problem I could ring them, and it would be the nurses who treated me and saw me all the time – they were the ones looking after all the patients.

63. I only saw the consultant when there was the initial move to the Neath General, and I saw Dr Godkin for the appointments to put me on the treatment and the appointments to confirm results at the end of the treatments. I mostly dealt with Tara and her colleagues (about 2 or 3 other nurses). They were the ones who got the dietician involved and took care of me. They were great with all problems.

Section 7. Financial Assistance

64. The initial payment was given to me after the Skipton Fund had contacted me. I expect they found out about me through the NHS. I was given an initial lump sum of £20,000, which was sent by cheque 6 weeks after the initial letter, this was in 2004.

65. I had to fill in forms for bank details, and had to confirm when I received the bad blood as there was a time limit and I just qualified. They also asked for consent to look at my medical records which I gave.

66. The corresponding letters said they hoped that the payment would go some way to compensating me, and if there were any new developments they would be in touch, which they have kept to. This included a couple of letters about the inquiry and also more payments, which were started within the last two years.

67. I will receive quarterly payments for the rest of my life. Currently, I get £4500 a year, it has risen by £400 since the original payment start date and includes a cold weather allowance.

68. The Skipton Fund changed to the Velindre Health Trust, when the Welsh Health Authority started dealing with it.

Section 8. Other Issues

69. I do feel angry, but the anger has reduced over the years. I still sometimes think why me? For both colitis and Hepatitis C, but at the end of the day, if someone has to have it, why not me?

70. All I want is for someone to hold their hands up and say, "look John, sorry". I want them to say they made a mistake. I don't care about people going to prison, but I see on TV that no one is taking responsibility and somebody should take responsibility for that decision to use bad blood. It was an error of judgment and should have been screened better but it is too late for retribution.

Statement of Truth

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

Signed **GRO-C**

Dated 12-2-19