Witness Name: Michelle Leaman
Statement No.: WITN0951001
Exhibits: **WITN0951002 –5**
Dated:
9th Aug 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MICHELLE LEAMAN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 04 June 2019.

I, Michelle Leaman, will say as follows: -

Section 1. Introduction

1. My name is Michelle Leaman. My date of birth is GRO-C 1954 and my address is known to the Inquiry. I was formerly an auxiliary nurse, but I am now retired due to ill-health. I intend to speak about my active infection with Hepatitis B. 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.

2. I confirm that I am not legally represented and I am not seeking anonymity.

3. I have signed a consent form for the use of my statement dated 03 July 2019 and I am happy for this to be used once my statement is signed.

Section 2. How Infected

4. I believe I was infected by a blood transfusion of two units given to me after the birth of my son in 1973. I received the transfusion post-partum as I had lost a lot of blood and required both internal and external stitches. This took place at the Torbay Hospital. I was kept in the hospital for a few days because I was very weak. I was not made aware of any risk of infection at this time, though I was observed in case I had a bad reaction to the blood transfusion, which they had warned me about.

5. From that time onwards, I noticed I was very tired and lethargic to the extent going to work became increasingly difficult. Around 1983, I started to notice the onset of flu-like symptoms without having the actual cold. I was suffering with aching joints and stiffness and was diagnosed with Rheumatoid Arthritis at the time. (though it later transpired this was a misdiagnosis).

6. In 2005 my health deteriorated still further and I had pain that led to a cholecystectomy (removal of my gallbladder). I had seen a doctor, I cannot remember which now, after the removal of my gallbladder and I recall they were confused about some recent blood tests and wanted to do some further blood tests and get some scans after I returned from a holiday which I had planned. However, whilst I was on holiday in Cornwall, I was taken ill. I had a fever and chills and I was in a lot of pain. I wanted to return to my usual hospital in Torbay, but I was not in any condition to travel that far so I went to the local Derriford Hospital and I was admitted there.

7. Derriford Hospital did quite a number of tests, though I do not recall them mentioning that they would test for Hepatitis. I was in a general ward with beds close to mine on either side. The doctor came in and drew the curtain around my bed and told me my recent blood tests

showed I had Hepatitis B, that it was a chronic infection and that I had fibrosis of the liver.

8. I was asked whether I had been with many sexual partners, but I explained I met my first husband when we were only 13 and had been with only him until I married my second husband and we were still together at the time of my diagnosis. I did not have any tattoos at that time (though I now have one in memory of my mother). I was asked about drug use, but I had never used controlled drugs. It was explained to me that the likely source of my infection was, therefore, the transfusion I had received in 1973. Up until the diagnosis, this was the only transfusion that I had received. [Exhibit WITN0951002].

9. I could not believe that they had told me of my infection in a crowded general ward and I feel I should have been taken somewhere more private. I was also alone at the time and so, once the doctor left me, I had no support. It was a very stressful time for me imagining all sorts of complications and with no one to reassure me.

10. I was given a leaflet about Hepatitis B and I was advised to see a gastroenterologist in Torbay and I was referred to Dr George. I was not given much information about managing the illness or infecting others because that was left to the consultant to do.

11. I am still infected with Hepatitis B and my viral load has recently gone back up despite treatment that is supposed to control the infection. I worry whether the medication is effective enough for me.

Section 3. Other Infections

12. I believe I was only infected with Hepatitis B. I was tested for HIV and Hepatitis C as I was advised I could potentially have been infected with either and the wait was nerve wracking, but both came back negative and that was a relief.

Section 4. Consent

13. I believe I have always consented to the treatment and tests I have undergone, other than as mentioned, when I was diagnosed with Hepatitis B. I wasn't actually aware they were testing for that. I had to sign something for the HIV/HCV test to show that I consented to it. I do not believe I was the subject of research or experimentation.

Section 5. Impact

14. Physically, the main symptoms of the infection have been exhaustion. The tiredness is off the scale. I only have so much energy and once I have used it up it is like someone has pulled the plug and I am no longer able to do anything past that point.

15. I was diagnosed with Rheumatoid Arthritis at 36, but it turns out I did not actually have this. I was told by my rheumatologist that the serology for Hepatitis and Rheumatoid Arthritis is very similar, hence the misdiagnosis [Exhibit: WITN0951003]. I did (and still do) have stiff and aching joints. I was given treatment for the Rheumatoid Arthritis with hydrotherapy, but after my diagnosis with Hepatitis B the man who gave me this treatment informed me out of the blue one day that I could no longer use the hydrotherapy pool. He was very apologetic and upset, but told me that I could no longer use it because I had Hepatitis B. My back and elbows in particular are affected and just recently, I made the connection between the increased pain level in my elbows and once again having a higher Hepatitis B viral load.

16. Recently, I was in hospital again due to the pain and the doctors believed that I might have pancreatitis or an internal bleed. However, it turns out it is not pancreatitis as the scans came back clear but I am frustrated and wish someone could give me answers. I was given morphine pain patches to help with the pain and I was incredibly

relieved as I experienced being pain free for the first time in ten years. I thought to myself that this must be what it is like to be "normal".

17. I have recently returned to my doctor as I am still unwell and I was experiencing increased fatigue (I now feel I need to sleep in the afternoons), nausea, pain and generally feeling unwell. I have been told my viral load has increased despite treatment and I might be experiencing resistance to the medication. I am awaiting some test results for this and I am anxious as to what the outcome may be.

18. Mentally, I have suffered from depression on and off since I was first infected in 1973, though I did not always attribute it to Hepatitis B before my diagnosis. I have been on anti-depressants (Citalopram) since then until I recently and gradually weaned myself off them. The reason I have come off the anti-depressants is because I am frustrated with doctors attributing any ailment to depression. The first question out of their mouths is always "are you stressed?" or "is anything stressing you?" and I feel they do not believe me when I know something is wrong. After all these years of problems, I know how my body works.

19. When I was first diagnosed, I felt dirty and walked around with an anti-viral spray and wipes as I feared I would infect someone. I would clean everything very thoroughly because I was scared. I worried about the safety of my family. I was absolutely devastated when I was diagnosed. However, I went on to experience a greater second wave of mental anguish, when it came out that the infections were due to infected blood that had been imported.

20. I have in the past suffered and still do from various other medical conditions that I now attribute to the Hepatitis B. I had my gallbladder and appendix removed and I feel if your liver isn't working properly and you have this poison, the Hepatitis B, inside of you then it cannot be doing you any good. I experienced chest pains and I was

diagnosed with a heart murmur. I have also been diagnosed with Steatohepatitis (fatty liver) [Exhibit: WITN0591004] and Fibromyalgia [Exhibit: WITN0951005]. I was informed Fibromyalgia is not uncommon in patients with Hepatitis B because it is an autoimmune issue and the Hepatitis weakens your immunity.

21. In 2017 approximately, I was diagnosed with Asthma. I have never had an issue with this before, but I developed a cough and I was unable to shake the infection. It developed into Bronchitis and then into Pneumonia and I was hospitalised. It was after this incident that I developed Asthma. I cannot take the normal medication as I get an increased heart rate, so I take a preventer instead.

22. My Asthma nurse says I am contrary as I do no present with anything with the usual symptoms. For example, I did not become jaundiced when I was in hospital for my Hepatitis B and gallbladder issues and I only experienced pain immediately before my appendectomy, which is why the surgery was left for five days.

23. I have not experienced an impact on any other treatment I have received, though I have to own up to the fact that this is because I have not told my dentist. I have all my own teeth and I would like to keep it that way so I have not told my dentist, though I am sure it is safe because they always wear gloves and have adequate hygiene practices.

24. I am always treated last during theatre procedures and surgery. I have never noticeably experienced being put in isolation, though I do recall being put in a room by myself once that felt like a prison cell because it only had a window in the roof, though I didn't realise at the time the possible implications of why I was put in there by myself. Otherwise, I think my treatment by medical professionals has been fine, though I do get the feeling there must be a stamp or something

on my records because I feel I am always looked at and treated with a bit of disdain. Although I cannot be sure of this, it does not feel nice.

25. My faith in doctors has been impacted too. I had a brilliant relationship with my previous doctor, Dr Thalheimer, as he was wonderfully supportive and caring. My new doctor, Dr GRO-D, and I have not formed the same kind of relationship, though I have been seeing him since my diagnosis in 2005 (with a short break whilst my treatment was in Exeter).

26. Dr GRO-D can be blunt and I recall he once said to me that people hear they have cirrhosis and think it is a death sentence, but I wonder if he would be as blasé about it if he were the one having scans to check for liver cancer. However, we have never had a falling out as such.

27. Socially, my infection has had quite a severe effect. Even before my diagnosis family social events were scheduled to minimise the impact on me, but since my diagnosis and the progression of my infection I continually feel awful and I don't want to go anywhere. When I was younger I would occasionally drink socially, but now I cannot drink at all. I used to travel a lot, but for a long time I was afraid to travel in case I became ill, though I hope I will now go on holiday regardless, though this does mean I will need to declare everything to my insurers.

28. I feel friendships have faded away, though I am upfront with my current friends about my condition. I remember going on holiday with one friend and as we were sharing an apartment I felt I had to tell her. She burst into tears when I told her because she had thought I was a lazy so-and-so sleeping in the afternoons and she felt bad that she had thought this about me as she had not understood that there was something wrong until I told her. She also used to laugh that I would carry antibacterial stuff everywhere with me. I joked that as we were

not having sex and I did carry antibacterial stuff everywhere with me that she would be fine. Fortunately, we are still friends, though due to circumstances with my health we do not see each other often anymore.

29. Fortunately, I have not experienced much stigma as I know it was very bad before for some people, though now it seems better as more people are aware and there is better education about the virus.

30. There was no impact on my education as I had completed school before my infection.

31. However, there was a significant impact on my career. I would struggle to go to work even before my diagnosis due to the fatigue I felt, though I would fight it. I did not know why I felt poorly so I would keep struggling through. My career progression was inhibited by this exhaustion as several nurses advised me to gain further qualifications and complete further training to become a nurse, but I knew I would be unable to physically.

32. I feel the illness affected my thinking ability, too, like a "brain fog". I would forget things or loose track of what I was saying or doing. I gave up work shortly after my diagnosis and the breakdown of my marriage as I was unable to cope with it anymore because I was too tired and too ill. I loved my job so I would not have given it up or taken early retirement (I retired just after 50) and I would probably still be working now if it was not for the Hepatitis B. I lost not only the financial support provided by my career, but the satisfaction and enjoyment I gained from working. I feel pretty redundant and useless without my career.

33. Financially, the impact has been considerable as I lost a lot of income from my employment by retiring early, though I struggled in whilst I was working so I did not lose out then. There are lots of costs

involved with being ill, but I am fortunate that I have no mortgage to worry about as I am renting. I have no life insurance, but I do have a funeral plan so my kids will not have to worry when the time comes.

34. The impact on my family has been extensive. My husband and daughter were tested and, fortunately, they were both negative and this was a relief, though the wait was agonising. I was particularly afraid for my daughter as I was worried that, had I infected her, she would be unable to have children. My son, Kevin, has still not been tested and this does worry me because I do not know if I have infected him.

35. My formerly happy marriage broke down after my diagnosis with Hepatitis B. My husband, Roy Maloney, was always very supportive and tried his best to help me, but I felt there was increasingly distance between us. I was terrified of infecting him and so I kept him at arms' length and this had a negative impact on our relationship. As I had a hysterectomy, we had never required contraception, though after my diagnosis we were advised to use condoms. I felt so dirty and afraid and depressed that I didn't want to be involved with him in that way.

36. I think caring for me and worrying about my health, and being around someone who was constantly worrying and anxious themselves, was draining for him. Slowly we stopped talking and drifted apart. To me it felt like I was living with my brother and not my husband. I feel guilty about the separation and about a lot of things. He now suffers from depression, too. Our relationship was never the same after my diagnosis and we separated in 2014.

37. Despite my illness being undiagnosed during my son and daughter's childhood, I believe I was a good mum and that I did the best for them. Kevin loved the beach and was content to play with his friends so I could just sit and watch. I always fought the tiredness for them.

38. My daughter has GRO-C and prefers that I do not talk to her about my illness as far as possible. It is very distressing for her and she finds it difficult to deal with. I have to lie and tell her that everything is fine. I am her advocate and look after her finances and paperwork, so I do worry about what will happen to her when I am no longer around. She lives in her own world and nothing bad happens in her world. She doesn't want to think about my infection because if she doesn't think about it then it is not there. She is happy and so I leave it like that.

39. I talk to my son about my illness more and I spoiled his last birthday as I spent it in hospital. He has made his own statement about the impact on him [WITN3537001].

40. I have two brothers and sisters and my illness has affected them, too. My sister, Susan Humphries, has told me that she has struggled seeing me go from a strong woman to someone who is constantly tired and in pain and cannot walk far without resting. This is because I have always been someone that the family could go to for advice and help. Susan has told me that she feels the illness has robbed the family of that to a certain degree because I have to constantly fight the illness to stay on top of it. That means they feel they are a burden when they come to me with a problem. Susan says that it makes her very angry because of the way I was infected and she feels that for years the issue has been ignored whilst people like me have had their lives destroyed. She thinks that, at the very least, someone should be held accountable.

41. I have tried to talk to my other sister about my infection, but she cries whenever I mention it and is afraid of what I will go through, so she cannot talk about it without breaking down.

42. My mother spent the last years of her life worrying about me and that is one of my greatest regrets. My mother had cancer and knew she

was dying and was worried that there would be no one to care for me. I tried to hide my separation from her to prevent worrying her more, but mum always knew and I could not lie to her. Mum would give me a look that said "I want the truth now" and she would always ask me if I was telling her the prettied-up version or the actual truth.

43. My mother worried about my health and about my finances. She worried herself to death about me. She would cry at times with the anguish so I always had to try and be upbeat. Latterly, I frequently felt that I could not talk to her about it in case I upset her. In the end, I avoided seeing her so that I would not upset her. I feel, had I not been ill, I could have cared for her more towards the end, but instead my sister had to do most of it without me. I regret putting my mother through that as well as my family.

44. I struggle because I feel everyone must be sick of hearing me complain and hearing about my illness (perhaps I wrongly think this), because I know that I am sick of it! I try not to bother my family as much as possible as I feel I cannot keep putting this on them.

Section 6. Treatment/Care/Support

45. I was diagnosed with Hepatitis B in 2005, but I did not start any treatment until 2012. I had regular blood tests every six months to check my viral load. I had a liver biopsy in 2005 which showed level 1 fibrosis of the liver. (See Exhibit WITN0951002) The ordeal of having the liver biopsy was horrific. In 2012, I had another liver biopsy that showed the fibrosis had progressed and my blood tests revealed a higher viral load so I was offered treatment at that stage.

46. I had discussed treatment options with my husband previously as our research showed there were a lot of side effects, but in 2012, my doctor informed me that it was necessary to start treatment to prevent further damage. I was prescribed, and I still take, one tablet of

Tenofovir a day. This medication does not cure Hepatitis B, but it does supress the viral load. I am now waiting to find out if I have become resistant to this medication as my viral load has increased again.

47. During the treatment I have experienced side effects, though many are similar to conditions I already suffered from. I have experienced nausea and I have been given medication to deal with this, though I only take it when I absolutely have to. I have also experienced fatigue and dizziness (and I feel this has increased lately, possibly as the effect of my medication has lessened). I have experienced hair loss, though it does not matter what I say, Dr George always says that it is nothing to do with my liver. I have recently experienced itching, too, on my arms, though I have never become jaundiced.

48. I have never been offered psychological support or counselling for my infection. I did attend a support group for a time at the Royal Devon and Exeter Hospital whilst my care was under them. However, I did not find this helpful as many who attended were patients who had undergone a liver transplant but were still drinking and I could not cope well with this. After my separation from my husband I no longer had transport as I do not drive and so my care returned to Torbay Hospital and they do not have a support group.

Section 7. Financial Assistance

49. I have received no financial support, other than from my family, and I have had to fight for any benefits I have received.

50. I was never told of the Skipton fund, or any other funds, by medical professionals, but I heard by chance about the Skipton Fund as a friend of my brother received some money from them. However, when I called them, I was informed there was no financial support for

people with Hepatitis B and that they only cared for individuals with Hepatitis C.

51. I have not bothered to approach EIBSS as I assumed it would be the same. It is unbelievable that there is no financial support for individuals with Hepatitis B when they suffer from chronic infection and similar symptoms and issues as those infected with Hepatitis C. After all, for many of us the source was also infected blood provided by the NHS without any warning of risk

52. I have struggled to get financial support from other means, too, and I have relied on my family as my mother and children would often give me money. Were it not for my daughter, I would have no clothes to wear! For a while, my only support was the basic level of ESA, which wasn't very much.

53. I now receive the most basic PIP, but I had to fight very hard for this and attend tribunals because I was "not sick enough" to get the support. My doctor asked for £25 a letter for a letter of medical support, which was more than I could afford at the time. Now that I have PIP, even though it is not a lot, it is the first time that I do not have to worry about money as much.

Section 8. Other Issues

54. It is not right that I was infected through contaminated blood and it was not my fault. It is unbelievable that it was ever allowed to happen and that people knew about it but did nothing. I feel angry. I don't think my life was ruined because I had a beautiful family, but I am annoyed and frustrated that I had to fight so hard for so long for even a little bit of support. I wish I could put people into my body so they could gain an understanding of how I feel daily. Because although I look fine, I do not feel fine!

Statement of Truth

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

Signed **GRO-C**

Dated 9/Aug/2019