Witness Name: Michelle Baulch
Statement No.: WITN0760001
Exhibits: **WITN0760002 –005**
Dated: 19/5/2019.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MICHELLE BAULCH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 February 2019.

I, Michelle Baulch, will say as follows: -

Section 1. Introduction

1. My name is Michelle Baulch. My date of birth GRO-C 1967 is and my address is known to the Inquiry. I am a mother of three children and eleven grandchildren. I was a home carer for disabled children and the elderly, but can no longer work due to physical and mental health problems. I have suffered from mental health problems since my childhood. I intend to speak about my experience of contracting Hepatitis C (HCV) and the treatment I received for it. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.

2. I am not legally represented. The investigator has explained the anonymity process to me. I do not require anonymity, as I want my

story to be told. I want to help others who have not had the chance to tell their story, and those who have passed away.

3. I criticise my former GP Dr Holland and my former consultant Dr Boyd in this statement. The investigator has explained the 'right to reply' procedure to me. I understand that my observations will be shown to Dr Holland and Dr Boyd and that they will have the right to make a statement replying to my criticisms.

4. It has been a while since this all happened to me; I have tried to recall the dates however these should be treated as a rough approximation and not as a definitive as my memory has faded over the years.

5. Exhibits to this statement refer to me using my former surname name 'Jones'.

Section 2. How Infected

6. On GRO-C 1985 my twins were born by emergency caesarean section at the Nevill Hall Hospital in Abergavenny. During the emergency procedure I haemorrhaged and consequently lost a lot of blood. I was given a blood transfusion with what I now know to be infected blood and contracted Hepatitis C.

7. For the first 18 years of life I had no blood transfusions and no illnesses symptomatic of hepatitis C. I had a miscarriage when I was aged around 14/15 due to a complication. Therefore, when I was pregnant for the second time with the twins, the consultant was worried the same complication would occur GRO-C. He was worried that I was likely to have another miscarriage. However, I wanted to go through with the pregnancy and see how far I could carry my twins.

8. Due to the increased risk of miscarriage, I was in hospital for periods of rest whilst I was carrying the twins. I was admitted to the Nevill Hall Hospital in Abergavenny at the request of the GP. I was in hospital for bed rest for about a month the first time, and the second time for two months. I kept going into premature labour and the doctors made me rest to prevent this developing.

9. On the day of the birth of the twins, I was doing day-to-day things at home with my mum. I could not move around a lot, as I was heavily pregnant. One baby was breach and the other was transverse, one was pressing on the nerves in my legs, which made the pregnancy incredibly painful. I went to see my midwife for a routine appointment and she the bought me home afterwards as she thought I was in slow labour. I was home for around 90 minutes when my mum phoned for the ambulance as I was in pain and distress.

10. I was in the hospital for 20 minutes when the heart rates of one twins dropped worryingly low. Doctors then decided that I needed an emergency C-section as they were afraid the baby might die.

11. My twins were born 8 weeks early via emergency caesarean. I required a blood transfusion as I had haemorrhaged. I lost a lost of blood during the C-section and required the transfusion to replace what was lost. I did not see my babies for two weeks after they were born because I was so ill. I was suffering from jaundice.

12. I can remember seeing the blood being transfused when I came around from the anaesthetic. I thought I was on a drip but I soon realised that it was blood. The medical staff told me I had to have the transfusion as I had lost so much blood. The doctors/consultants on the ward told me I had to have it to replace the blood I lost during surgery. My mother was with me at the hospital. I remember my mum coming to see me when I was unwell, as well as my sisters and my in-laws. No one could understand why I was yellow.

13. I suffered adverse reactions to the blood, I was yellow I felt very fatigued and I had no energy. I felt very unwell in myself I could not understand things. The Doctors spoke to my mum as I had difficulties understanding. I also suffered really bad headaches and stomach pains. I just felt that there was something wrong but I just did not know what.

14. I was discharged 4 weeks after giving birth to my twins. The medical staff did not discuss the transfusion with me afterwards. The twins were kept in hospital. I had a girl, and a Boy. GRO-C

GRO-C

15. After being discharged from hospital, I was back and forth visiting various GP's, as I was generally not feeling well in myself. The doctors failed to give me a reason why. My body did not feel right I felt strange; I knew that there was something wrong. I was very fatigued, my body hurt all over and I had joint pain. I had lots of headaches, I could not think straight. I had hives and lots of itchy patches on my skin. I was frequently going jaundice. The doctors put this down to me drinking alcohol. At this point in my life, I was an alcoholic.

16. However, I knew that my symptoms were not attributable to the drinking; I knew that there was something wrong inside me. Doctors did not do any blood tests. They also put my illness down to my mental health at this stage. I would attend the GP once per fortnight between November 1985 and the summer of 1986 when I moved to Germany.

17. I moved to Germany as my then husband was in the military, he served in the Royal Regiment of Wales. I would visit the military doctor for the on going symptoms that I have discussed above. The military doctors put my symptoms down to drinking and my mental health problems; I still did not have any tests.

18. In 1988, I fell pregnant with my third child who was born GRO-C 1989. Doctors took blood tests when I was pregnant. As far as I was aware my blood test results were normal when I was pregnant, no concerns were ever raised by doctors. I also had to go into hospital for bed rest with this pregnancy but other than that, it was a normal pregnancy with a normal birth. However, I still felt restless and was irritated by the same symptoms as described above during that pregnancy.

19. After the birth of my third child, I just got on with my day-to-day life looking after my children. Despite still feeling unwell, I managed to go to work; I worked making ammunition for the military.

20. After this in 1990 we moved to Hong Kong with the military until 1993. In 1992 I had a hysterectomy, I had a second blood transfusion during this operation as I haemorrhaged.

21. I can remember having the second blood transfusion. I can remember waking up seeing the blood hooked up to the drip with the clear solution as well. After receiving this blood I went yellow again. The doctors said that I had the transfusion because I bled heavily during the operation and that the blood lost, had to be replaced. I remember that my skin was yellow all over.

22. The military doctors in Hong Kong did blood tests when I was in hospital. During the second week in hospital, a week after the tests were done, I got the results. The consultant told me that I had Hepatitis B.

23. The doctor wanted to know how I had come to acquire the disease. He wanted to know if it was sexually transmitted from a partner, or if any sexual partners of mine could have contracted the disease from any of their previous partners. He also asked if I had any other blood transfusions I told him I had. He did not suggest an opinion to me of

how I may have contracted it. He also did not suggest any treatment for the hepatitis B at this time. I was in hospital for two weeks for this hysterectomy.

24. I was discharged in the summer of 1993. We continued living in Hong Kong and I made life as good as I could for my children. Following the hysterectomy, I went to GP for check ups; he told me I may have contracted Hepatitis through sexual transmission. I did not understand what this meant at the time.

25. I was diagnosed by the Hong Kong Military Hospital with arthritis after I had the hysterectomy, in my joints, knees elbows. I was on anti-inflammatory tablets and painkillers. All of the symptoms I have described already were still there on top of the arthritis.

26. In 1993, we moved to GRO-C in the UK. I was seeing the GP there who only prescribed arthritis medication for me. We were living in GRO-C Wiltshire in 1995/1996. During this time I was unwell, I was jaundice and was in pain and itching a lot. I knew that there was something wrong with me but again I did not know what.

27. The GP arranged for me to be seen at the Queen Elizabeth Hospital in Birmingham. There I had a liver biopsy and other tests. The doctors in Birmingham finally diagnosed me with Hepatitis C in December 1996. They asked me how I got Hepatitis C. They suggested various ways I could have contracted the disease, sexual partners, using drugs, sharing needles. I told him about my two blood transfusions to which the doctor made no comment. They told me treatment was not available at that time for me.

Extract from *WITN0760002* - Letter to Dr Davies from Dr David Mutimer dated 2 December 1996

'Apparently there had been a prior infection with Hepatitis B virus but serology confirms that she is now Hepatitis B virus negative. Her serology confirms hepatitis C infection and her liver function tests are deranged consistent with hepatitis C'.

28. They did not make me aware of what the treatment was or what it entailed. I went back for routine appointments every 6 months then eventually every year. They took blood and biopsies but did not tell me the consequences of having Hepatitis C.

29. I moved to Wales 1996/1997. I was going back and forth to see Dr Boyd at Nevill Hall Hospital. I remember having blood tests and liver biopsy's and general check ups, I went every 6 months, still I had no information about my disease. I also had around 3 scans of my liver. The first scan took place in summer of 1998 this scan showed scarring of the liver and craters on my liver, they said it was chronic but mild.

Extract from *WITN0760005* - Letter from Dr Eric Boyd to Dr Hutton on 28 August 1997 re a look back study identifying the witness

'Very recently here she had a repeat liver biopsy which showed only the mildest of chronic persistent Hepatitis with essentially normal liver function tests'

30. The second scan was around December 1998 this revealed the same as before. Scan number 3 was around December 1999, which also showed the same outcome as the others.

31. I was in the dark with the disease nothing was explained to me. I still had the same symptoms and was in pain all of the time. I went back to

the GP who put it down to my drinking and mental health. The hospital was very blunt with me. I stopped drinking in 1997.

32. The consultant in at Nevill Hall Hospital made me believe that I had contracted the Hep C in Hong Kong; as a consequence of the blood transfusion I had as a result of my hysterectomy.

Extract from *WITN0760005*- Letter from Dr Eric Boyd to Dr Hutton on 28 August 1997 re a look back study identifying the witness

'Mrs jones has been assessed by the Liver Unit at Birmingham who felt that her Hepatitis was so mild that no therapy was required, and very recently here she had a repeat liver biopsy which showed only the mildest of chronic persistent Hepatitis with essentially normal liver function tests, so a decision was made not to institute any therapy for her…

I suppose that, in the light of the above and the fact that she has adjusted well to the situation, there is probably not a lot to be gained at the present time by telling Mrs Jones where and when she was infected.'

33. I went to Nevill Hall Hospital on several occasions to see consultant Dr Boyd. On one particular occasion I went to see Dr Boyd with my mother, he was quite rude to me. I believe this was because I was an alcoholic before and have mental health problems. He called me a '*Hypochondriac*'. He examined my chest and neck, but did not do the routine examination of my stomach area. He said he would send for me with my next appointment.

34. I then moved to my current address and lost contact with the hospital. I had not been seen at a hospital by a hepatologist for a few years. I was going back and fourth to the GP Dr Holland who made a referral for me to see the haematology nurses at the Royal Gwent Hospital. I went to see the hepatology nurses and they took blood tests. They said treatment was not recommended for me at that time.

Extract from *WITN0760002*- Letter to Dr Davies from Dr David Mutimer dated 2 December 1996

She was reviewed by my colleague, Dr Elwyn Elias, and it was his judgement that treatment was not indicated at present. We would recommend that liver biopsy is repeated some time in 1997. She may be suitable for antiviral therapy at some stage in the future'.

35. I continued to go back and fourth to GP with the same symptoms; pain and itching, it got to a point when I thought it was all in my head. I saw my GP frequently and they finally discussed treatment in 2009. Dr Holland referred me to the Gwent hospital again where they finally offered me treatment on 21 May 2009 for a 48 Week period. I was treated with Pegylated Interferon and Ribavirin.

36. There was a discussion around treatment before I had it. I had blood tests done. The doctors explained to me the type of treatment they could give me and gave me a couple of weeks to think about it. They described that it would consist of daily tablets and an injection in the stomach every week. They discussed some side effects saying that the treatment could make me feel generally unwell, making me feel nauseous and fatigued. I decided that I wanted treatment and began treatment on the date stated above.

37. I went to the hospital every 4 weeks to have blood tests done and to pick up my tablets. Doctors told me to have food with my tablets. They explained to me how to do the injections which was like an insulin pen. They showed me to pinch my stomach and insert the needle. They told me to use a clean surface and to dispose of the needle into a sharps box, which would be disposed of at the hospital. There were occasions when I could not go to the hospital so the hospital doctors/nurses

travelled to the GP surgery to see me there and to give me my medication.

38. It has only been over the last few years that I have understood the dangers of Hepatitis C, no one had ever explained it to me before. I was not aware of the risk of infection if I cut myself and was bleeding for example. I was not made aware of these serious risks. I was not aware that I could pass it on from blood to blood. It was only when I had my treatment that I was given a leaflet telling me if I bled to cover it up, to clean my blood up with bleach. I now know that it is a deadly disease that affects the whole body. I believe that my joint, muscle and neuropathic pain are all related to the Hepatitis C.

39. I worried that I might have passed it on my youngest son, which was a massive concern to me. I breast-fed him for two and a half years. I was only aware from the leaflet that I could pass it on.

40. None of the doctors or nurses ever explained properly to me about the diseases this made it very scary and daunting.

41. I did not understand what this diagnosis meant, I felt like my body was not mine anymore. I felt like there was something inside me crawling about which caused me to itch and scratch my skin. I was worried because I did not understand what was going on.

42. The only information I received about my illness was a little leaflet, given to be before I started my treatment. It said that if I have any cuts to clean the blood with bleach, which will kill the infection. Blood to blood transmission was also detailed in the leaflet. It advised me to be careful with sexual intercourse and menstrual blood.

43. I do not believe that I was provided with adequate information. The leaflet was helpful but it's all that I was give since being diagnosed with the illness.

44. I believe information about my illness should have been provided to me when I was diagnosed. Medical staff knew I had three children and a partner and they gave me no information on how to protect my family. I am appalled by this system. I feel like I have been neglected knowing that I had Hepatitis C, a serious virus that could be passed on to anyone.

45. I believe that the results of tests were communicated poorly, not in the right way. I was appalled by the medical professionals who did not tell me what illness I had as soon as they knew. They made me believe that I had caught the virus elsewhere when they had information about when and where I caught the virus. I do not think they gave me the right information to protect others and myself. I did not know the risk factors.

Extract from *WITN0760004* - Letter from Dr David Hutton, Consultant Haematologist, the Welsh Blood Service to Dr Davies dated 23 July 1997 re Hepatitis C Look Back Michelle Jones (Baulch).

> *'I understand that this lady has been diagnosed with Hepatitis C. It is now well known that she received a transfusion of whole blood in October of 1985 at Nevill Hall Hospital in connection with a Caesarean section, which was donated by a person who is now known to have tested positive for antibodies to Hepatitis C. It is therefore likely that she has been infected since that time.*
>
> *I have not been in touch with Michelle Jones concerning this but obviously it will have some effect on her follow-up.*

If you feel it would be helpful for me to make contact with Michelle Jones and provide her with any further information concerning this I would be very happy to undertake this.'

46. The only information I was given was a leaflet but there was a significant time lapse before I was provided with this. This created a big risk for my family and me. The leaflet explained about cuts and bleeding but did not go into depth and provide sufficient information.

Section 3. Other Infections

47. I been infected with Hepatitis C and I also am Hepatitis B antibody positive.

Section 4. Consent

48. I was treated with a blood transfusion that I did not consent to. I appreciate that I haemorrhaged which made my treatment an emergency, but I did not consent to being treated with infected blood. I expected to go into hospital and come back better not with a serious virus, which would cause me serious health problems for the next 20 years to come.

49. I have sometimes had blood tests and did not known what they were for. I feel that I was not fully aware of what doctors were testing me for.

50. I do not believe as far as I am aware that I have been treated for the purposes of research.

Section 5. Impact

51. The treatment I under went for Hepatitis C had a huge impact on me. I was in a lot of pain and lost a lot of weight around 3.5 stones. I had no appetite I was vomiting quite a lot. I was tired, drained and in a lot of pain. I had to wear a wig from the hospital because I lost so much hair.

52. I was prescribed a course of treatment for 48 weeks, however, one month before the end of the course, I had to be taken off the medication due to a mental health breakdown. The treatment put me in a really dark place; it brought all of the events of my past up. I was not mentally well; I struggled to cope throughout the treatment. My mental health deteriorated to the point that I was admitted into a psychiatric hospital. The doctors then stopped the treatment as they saw the impact it was having on my health. The doctors thought it was the medication, which caused this breakdown.

53. The treatment cleared the Hepatitis C virus, despite the side effects I responded really well. I had a blood test done last year at the Royal Gwent hospital, which confirmed that I am still free of Hepatitis C.

54. In the years after the treatment I saw my GP with chest infections and asthma. During the treatment and afterwards I was having chest infections. I have now been diagnosed with Chronic Obstructive Pulmonary Disease (COPD). I visit the GP frequently with my chest and the pain. I recall on GP, Dr Holland, calling me a '*Hypochondriac*', putting my symptoms down to my mental health problems. I have now been diagnosed with neuropathic pain, muscular pain and skeletal pain. I attribute this to the Hepatitis C treatment. I have now been prescribed several painkillers.

55. Having Hepatitis C has had a big impact on my mental health. I believe that I have not been well since then and I think my mental health has got worse. I attribute this to the Ribavirin/Interferon treatment.

56. I have suffered lots of physical health problems as a result of the treatment; I suffer from pain, jaundice, hair loss, weight loss, appetite loss. My appetite has not been the same since my treatment; I go without food, which worries my family. I do not feel hungry since the treatment. I have aches and pains all over but the worst are in my legs going down to my ankles, I also suffer with pins and needles in my feet. I am tired all of the time. I do not sleep well; I am on a lot of medication that helps me to sleep. I find it difficult walking around and I cannot walk far as I find it very painful.

57. I have faced lots of difficulties and obstacles when attempting to access treatment. The GP tended to dismiss my calls for help. I have been called a hypochondriac. I feel like doctors have not taken any notice of me, I have been ignored. I wanted therapy but doctors said that my hepatitis was so mild that treatment was not required. I wanted treatment to rid my body of the virus and to go and live a full and productive life. This decision not to treat me was taken by doctors behind my back with no input from me. I wanted treatment given to me much earlier; doctors were making decisions about me health without consulting me. I am saddened and disappointed by such decisions being made without them being discussed with me.

Extract from *WITN0760002* – Letter to Dr Davies from Dr David Mutimer 2 Decemberm1996

She was reviewed by my colleague, Dr Elwyn Elias, and it was his judgement that treatment was not indicated at present. We would recommend that liver biopsy is repeated some time in 1997. She may be suitable for antiviral therapy at some stage in the future'.

58. I told my dentist that I had Hepatitis C, after he was aware of my illness he wore long gloves and a mask every time I saw him. I had small operation under my tongue during which, the dentist wore safety

clothing, a mask and really long gloves. This made me feel really degraded. It is really not right to treat people like this. I would like the dental profession to be more sensitive, they should explain what is going to happen during procedures to patients so they know what to expect.

59. I have always had nice teeth, since the treatment I have lost all of my teeth, I now have to wear false teeth and my gums are all misshapen.

60. Being inflected with Hepatitis C has had a big impact on me especially not knowing the consequences of having Hep C. Knowing that I could have passed it on to any of my children is a worrying thought. I was not fully informed. GRO-C

GRO-C

61. My other children have not been tested. It had a big impact on my children seeing me go through the treatment. To this day I believe that they still cannot cope with it.

62. Having Hepatitis C has had a massive impact on my social life, I do not socialise. I have two friends but they have to come over to my house to see me, as I feel anxious when I go out. I do not like going to crowded places as this causes me to shake a lot, it makes me feel angry and feel like I have no control over what comes out of my mouth. I feel as if people look at me and then this causes me to react.

63. I remember when I was going through the treatment; people thought I was a Heroin addict due to my weight loss. I go in the car everywhere to avoid people's comments. As soon as you mention Hepatitis C people think the worse. It is shameful how people look at it, not knowing and understanding it.

64. I was a home carer and I had to give up the job because of the Hepatitis C. I always wore an apron and gloves to go into peoples house, I was fearful of passing Hepatitis C my clients.

65. However, my career came to an abrupt halt when my husband phoned my employer without my consent informing them that I had Hepatitis C. Following this conversation, I was called into a meeting with my supervisor and the boss to discuss how hepatitis C affected my work. I was told that I was a high risk to the clients. I was in the meeting for around an hour during which they completed a risk assessment.

66. The risk assessment found that was that I was a high risk to clients. My employer gave me the option to give my notice in. They effectively asked me to leave. I was disappointed as I enjoyed my work.

Financial effects

67. Having Hepatitis C has had a major financial impact on me. I was on very little money when I was asked to leave work. I was on low income; I went onto benefits to survive. I consider myself in poverty; I was living on £56 per week from which I had to pay all of my bills.

68. I had to rely on my best friend who made sure that I had food. She would make it for me or give me a bag of food. I would ask for money from my son. This was not fair at all. I think the government should provide for people who are in the same situation as I am, they should step forward and help people out more. I am not able to work any more. I would love to go out to work but my mental and physical health means that I am unable to do it.

69. Having Hepatitis has been hard on my whole family; it has been difficult to protect them from the stigma. I am a grandma and my grandchildren have been sheltered from my illness. My first husband left me, as he could not deal with me having hepatitis C. This resulted in me having a mental breakdown. We were together for 27 years.

Section 6. Treatment/Care/Support

70. I feel that medical professions have repeatedly turned me away when I ask for help. Its like they devalue me as a human being and tell me that it is all in my head.

71. I have never had any counselling or psychological support. I think I would benefit from this. Today the Inquiry investigators have made me aware of the British Red Cross support line and the services that I can contact to support me after giving my statement. I will give some thought as to whether this is appropriate for me.

Section 7. Financial Assistance

72. In 2005 I received a stage one payment from the Skipton Fund amounting to £20,000. I had no further support until around Easter 2017. In 2017 my late partner researched the financial schemes for me. He researched the Skipton Fund online and he learned that I was entitled to more money.

73. I have received money from the Skipton fund, and the Caxton Fund. I now receive my payment from EIBSS. As of 2017 I have been receiving £333 per month and recently I started to get £362 per month. I also have the special mechanism payment of £1536 per month.

74. My late partner found this all out on the Internet there was never any information about this physically given to me. I found the process to apply for this money was very confusing. My partner had to fill in the forms for me because I am dyslexic.

75. In order to receive the special mechanism payment I had to get a note from the hepatology department saying that Hepatitis C had had a big impact on my physical and mental health. I had to spend money adapting the house, as I could no longer move around as I once could. I had to have a walk in shower installed as I kept falling out of the bath.

76. I am aware that I may be entitled to other payments. I believe that the schemes should get in touch with people and not make it difficult to find them or to apply.

Section 8. Other Issues

77. I feel that treating people with infected blood imposed a death sentence upon people. I feel that the government and the blood service have not treated people fairly. I think people should have been compensated years ago.

78. We did not ask for this to happen to us, especially when the medical profession knew that the blood was contaminated and administered it regardless. I think we have to speak up for everyone, especially for those who have passed away who did not get the chance to put their story forward. I believe that this could have all been dealt with years ago.

79. I believe that the blood service knows every person who has received this contaminated blood. The service knows each and every person who gave the blood and can trace it back. The government is shameful; they should do more and compensate everyone. The ones who have lost children, partners loved ones should also be compensated in the same way that infected people are.

80. The government should stand up and take responsibility, especially the blood service; they should stand up and do something about it for

people who have been contaminated with Hepatitis C Hepatitis B and AIDS. This scandal has destroyed people and their families.

Statement of Truth

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

Signed 19/5/2019

Dated GRO-C