Witness Name: Susan Taylor
Statement No.: WITN1990001
Exhibits: WITN1990002 – WITN199015
Dated: 10 December 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SUSAN TAYLOR

Section 1. Introduction

I, Mrs Susan Taylor, will say as follows: -

1. My date of birth is GRO-C 1962. My address is known to the Inquiry.

2. I live with my husband in GRO-C close to our family and friends. I am a housewife.

Section 2. How Infected

3. I was infected with the hepatitis C virus (HCV) from a blood transfusion of plasma/FFP, at Freedom Fields Hospital, Plymouth, Devon in 1983. I was given a blood transfusion after I had a miscarriage and haemorrhaged, leading to a significant amount of blood loss.

4. Although I can remember having a blood transfusion, I don't recall being given any prior advice about the risks of possible exposure to infection from a transfusion or signing a consent form to go ahead with the procedure.

5. I found out I have been infected with HCV as follows. In 1990, I travelled with my husband to GRO-C, USA, to live with him and support him through his Airline Pilot Training Course. A few months after we arrived in the States and my husband had settled into his training course, I started feeling unwell, with hot and cold temperature, extreme tiredness, nausea, no appetite and middle to low back ache (after a long period of standing in one place, I had to lean on a chair or table, to take the weight off my back).

6. My husband took me to a local doctor's surgery and I was examined by a male doctor, whose details I cannot recall or find documented on my medical records. He confirmed that my temperature was high and he prescribed me some antibiotics.

7. My tiredness and back ache and pain increased to a point where I found it difficult to concentrate, struggled to get through the day, took regular naps and started going to bed earlier at night. After returning to see a doctor and having two blood tests, I received a telephone call in November 1990 with my blood test results and was told I was HCV positive.

8. I attended a pre-arranged hospital appointment with a Professor Lee in South Dallas. After realising the huge cost for treatment in the USA, Professor Lee referred me over to the treatment and care of a Professor Roger Williams at the Cromwell Hospital (a private hospital) in London and gave me a letter to take to my appointment. I cannot recall the name of the hospital I attended in South Dallas and I did not retain a copy of the letter given to me by Professor Lee with details of the hospital.

9. My husband drove me to Cromwell Hospital and attended my consultation with Professor Roger Williams in January 1991. He provided minimal information

about HCV due to the fact that it was only discovered in 1989 as a result of Non-A Non-B Hepatitis. Therefore I received insufficient knowledge to help me understand and manage the infection.

10. Prior to my diagnosis, we had planned to try for a baby. I asked Professor Williams about the likelihood of passing the HCV to a foetus. He advised me that there had been no known cases of cross contamination from HCV to a new born baby. However, my husband and I were not convinced or satisfied, given that HCV infection is blood borne and too high a risk. So we decided to wait until after my treatment and hope to be HCV cleared before trying for a baby.

11. It wasn't until over ten years later, at the time of my first relapse with chronic HCV in around 2001 to 2003, under the care of Professor Gilmore at Royal Liverpool Hospital, that I was made aware of the risks of others becoming infected. Professor Gilmore informed me that there is a high risk of HCV cross infection to an unborn foetus. He also advised us to avoid sharing any personal care items that may carry blood on them, such as razors, toothbrushes, scissors or nail clippers and to always disclose my HCV status to other health care professionals. This was the first time I had received this much information about HCV.

Section 3. Other Infections

12. Following my blood transfusion in 1983 and to the best of my knowledge I do not believe I have been infected with any other viruses in addition to HCV as a result of being given infected blood.

Section 4. Consent

13. To the best of my knowledge, I do not think I have ever been treated or tested without my knowledge or consent or for the purposes of research in relation to HCV.

Section 5. Impact

14. Before setting out the impact of HCV on my life, I will first set out my treatment history because I have suffered two relapses of HCV and I cannot set out the impact of the infection on my life without explaining the effect these relapses and subsequent rounds of treatment have had on me.

First round of treatment for HCV, 1991

15. In 1991, after undergoing a liver biopsy and further tests which confirmed I had Genotype 1b disease, Professor Roger Williams immediately made arrangements to start my first six months course of monotherapy with Interferon Alpha treatment.

16. I had to return to the Cromwell Hospital, London, for an overnight admission to receive my first intramuscular injection of Interferon. My husband had to pay for my overnight stay, first injection and for me to call a nurse during the night for paracetamol to help reduce my fever, which is a normal symptom caused by Interferon after the first dose. I am unable to recall a clear reason why Professor Lee arranged for me to be referred to a private hospital rather than an NHS hospital in the UK. We were, however, informed that although new treatments had started in the UK (in the private sector), they were still in the early phase and not so widely available on the NHS.

17. It was then arranged through my GP, Dr Swift at Wallasey Village Doctors Surgery, Wirral, to find funding from the GP practice in order to pay for my six months of treatment. I had to collect supplies one week at a time from the pharmacy close to my doctor's surgery and keep the vials at a set temperature in my refrigerator at home. The treatment was successful and I achieved a sustained viral response (SVR) 12 months post treatment. A letter from my gastroenterologist dated 6 January 2003 confirming I was PCR negative 12 months after treatment ended **WITN1990002**. The letter notes that my liver

enzymes were normal and previous liver biopsy had only shown minimal activity. I was therefore 'unlikely to develop any form of chronic liver disease'. I was discharged from the clinic.

First relapse of HCV, 2001

18. From 1995 to 2000 I began to feel generally unwell, extremely tired and weak, with joint and muscle aches and pains, anxiety and low mood. In 2001, after a blood test, my GP Dr Tucker sent me a letter advising that my blood test results were positive for HCV and that I had relapsed.

Second round of treatment for HCV, 2002

19. Dr Tucker referred me to the Royal Liverpool Hospital under Professor Gilmore and Doctor Lombard. After six monthly monitoring with blood tests and a liver biopsy, it was confirmed that I had Genotype 1b disease.

20. I started a six month course of combination treatment with Interferon intramuscular injections and Ribavirin tablets in 2002. I responded well to treatment and remained PCR negative from three weeks into treatment to 12 months post treatment. I was discharged from the care of the Royal Liverpool Hospital in January 2003 with a sustained virological cure.

21. In February 2002 I completed my 12 months Access to Health Nursing Foundation Course and started my Adult Nursing Diploma Course in March 2003. I struggled most days with the side effects of treatment, which included increasing tiredness, night terrors and sleep paralysis, muscle jerks, body weakness, difficulty concentrating (brain fog) and needing to nap during the day.

22. In 2005 my husband was offered an opportunity to work in Adelaide, South Australia and, having completed the Access to Health Course and 18 months of my training course in Adult Nursing, I decided to take a break to accompany

him overseas. After 12 months as a temporary resident in Australia, I applied and was accepted as a permanent Australian resident.

23. I trained and worked for a Company called Healthscope Pathology, as a Phlebotomist and Pathology Collector with auxiliary nursing duties. I was promoted to run my own clinic within a doctor's surgery in Adelaide.

Second relapse of HCV, 2011

24. In December 2010, I started to feel generally unwell, with increasing tiredness and nausea. After an appointment with Dr Middleton, he arranged for me to have some blood taken the following morning to check my LFTs, FBC and hormone levels. I returned to see my doctor and he explained that the results showed that my LFTs were elevated and confirmed that I was experiencing the menopause.

25. I had to stop working due to the increasing tiredness, back aches and pains and we made a joint decision to travel back home to the UK.

26. In around April 2011, I went to the Liverpool Tropical School of Medicine (LSTM) with my husband GRO-C The doctor also checked me and decided to take a few blood samples GRO-C Dr S. Todd at LSTM rang me at home with the results, informing me that I had relapsed a second time with a positive HCV PCR. This came as a huge shock and I broke down in tears. It took me some time to come to terms with the result.

Third round of treatment for HCV, 2012

27. I was referred back to the Royal Liverpool Hospital under Dr Smart. After a further liver biopsy and ultrasound scan, I was tested to establish my genotype at the Royal Liverpool and Broadgreen University Hospital Tropical and Infectious Disease Unit, under Dr Emmanuel Nsutebu. A letter dated 13 October 2011 from Dr Nsutebu to my GP, 'interestingly although she reports a

previous genotype 1b, the genotype which we found in July 2011 was genotype 4d **WITN1990003**. She is certain that she hasn't had any risk factors which would have led to her acquiring a new genotype in between her treatment in 2001 and recently. The first thing we need to do is clarify what genotype she has and I therefore plan to find her old notes to confirm whether she had genotype 1b as well as repeat her genotype today. I am expecting that it will be genotype 4d. It may be that she was likely infected in the past with two genotypes, genotype 1b and 4d and the relapse on this occasion is due to genotype 4d. She understands that the latter rate of success with pegylated Interferon and Ribavirin for 12 months with genotype 4d is, in the order of 40%. Since she is symptomatic, she is keen to have treatment and I therefore feel that it is reasonable to refer her for treatment irrespective of her genotype [...]'

28. A letter from my Hepatitis C nurse dated 26 January 2012 pre-treatment and setting out a summary of my initial diagnosis, relapses and treatments: 'Susan attended the nurse led Hep C clinic today for assessment to hopefully start treatment for her Hepatitis C virus **WITN1990004**. She has previously been treated twice for her Hepatitis C virus. She was in fact genotype 1 previously in 1991. She had monotherapy with Interferon. She did achieve SVR 12 months post-treatment. However, it was discovered in 1994 that she was PCR positive again and was therefore re-treated in 2001 with standard Interferon and Ribavirin for six months, again achieved SVR 12 months post-treatment and was discharged from the clinic in 2003. This lady the[n] emigrated to Australia and was in fact tested again in 2005 and was shown to be PCR negative then. On returning to the UK she became unwell. She was re-tested in May 2011 and was in fact PCR positive with a genotype showing of 4d [...] I have simply discussed all the possible side effects with the lady and how to manage them [...] and for her to start treatment at our next available slot.'

29. I started my 12 months course of combination treatment with pegylated Interferon and Ribavirin in February 2012, completing the treatment in January 2013. A further blood test done on the 1 August 2013, at my request, showed

that I had achieved a sustained viral response (SVR). The treatment had once again been successful in clearing my HCV and I was discharged from the gastroenterology clinic, Royal Liverpool Hospital on 31 January 2014 with a virologic cure. A letter dated 31 January 2014 from my specialist nurse to my GP confirming, 'this lady has completed her Hepatitis C treatment 12 months prior to her appointment today. Her HCV PCR is negative at 12 months post-treatment [...] this lady has now been discharged from our clinic.' **WITN1990005.**

30. Mentally, the impact of my HCV infection has caused me to go through a very low period of depression caused as a side effect of combination treatments of Interferon and Ribavirin. I still struggle to cope with the intermittent emotional ups and downs and this is distressing. When I feel anxious, really tired and low, just a simple, insensitive remark or gesture made in my direction can upset me.

31. I find it difficult to concentrate or stay focused on whatever I am doing at that time. My memory is poor, which is very embarrassing, frustrating and upsetting. I get spells where I can't think clearly, cannot recall what I have just been doing, and at times when trying to keep up a conversation my response is delayed or I am unable to understand what people have said to me.

32. When I feel misunderstood, am unable to explain something properly or am unable to remember a word or make reference to a particular example or point to help make sense of what I'm trying to say, it comes out wrong and leaves me feeling like a babbling fool, exhausted, frustrated, embarrassed and a failure.

33. When I feel tired and drowsy my speech becomes slurred and my voice drops, making my voice tone sound deep and hoarse. I find it hard to tolerate loud noises, such as busy, crowded places and bright lights hurt my eyes and I have to cover them or turn away. I experience mind blanks in the middle of a

thought or mid-activity and forget what I was I thinking or doing seconds before.

34. Shortly after starting my second treatment for HCV relapse in 2002, I began to develop sleep problems of partial seizure-like episodes at night and sleep paralysis. As I drift off to sleep, I feel a buzzing sensation in the centre of my forehead, sudden electric shocks in my head and a sense of falling backwards with an overwhelming feeling of fear and terror as if I don't know where I'm going. Suddenly I open my eyes, terrified and with the feeling of a heavy weight on my chest as if something is holding me down and I am unable to move my body. I often see or sense a presence and the room is unfamiliar, such as the design on the curtains is different, or the door is in the wrong place. I try to shout "help" and think I'm shaking my husband until I fully wake up and find myself in the same position as when I fell asleep and able move my body again. I sometimes have an episode as above, but without the paralysis.

35. During the day, I also struggled with anxiety and panic attacks, fatigue, body weakness, muscle and joint aches and pains, nausea, breathlessness, dizzy spells, disorientation, confusion, brain fog, drowsiness and an overwhelming need to sleep. My doctor started me on 10mg of Citalopram, increasing the dose to 20mg.

36. After my third treatment for HCV relapse in 2012, I started to experience more frequent daily episodes of dizziness, brain fog, a lack of concentration, disorientation, an inability to walk straight without swaying from side to side, uncontrolled drowsiness with an overwhelmingly strong urge to fall asleep, drifting in and out of consciousness (non-epileptic seizures), uncontrollable muscle jerks, sudden and painful heavy weight-like feeling or a weak hollow sensation in my thighs, nausea, anxiety and mood changes. My voice drops to a deeper tone and my speech is slurred.

37. From 2013 to date I find I need to take regular naps during the day and experience between one and four episodes a week of night terrors, both with or without sleep paralysis, as described above.

38. My GP, Dr Alam, referred me to the neurology department at the Walton Hospital with suspected narcolepsy and cataplexy.

39. I attended Walton Hospital on 5 July 2013, to see Dr Aji, a consultant neurologist. After my consultation and having reviewed EEG results and medical notes from 2005, Dr Aji diagnosed me as having a REM behavioural sleep disorder, parasomnia and possible mild narcolepsy. He started me on Modafinil 100mg (one tab daily) to help me stay awake during the day and to enable me to carry out my daily activities. After working well for about six months, my symptoms increased and the Modafinil became less effective, lasting for only two hours. My GP increased my dose to a maximum of 400mg to be taken as one dose on waking.

40. My blood test results post HCV treatment in 2014 showed that my electrolytes, urea and creatinine (EUCs) were deranged and my sodium level was low (127). After continued monitoring, my sodium levels decreased (126) and my GP referred me to Dr Daryanani at Clatterbridge Hospital nephrology clinic for further investigation (see **WITN1990006** regarding my urea, electrolyte, creatinine and sodium levels).

41. My first appointment with Dr Daryanani was in December 2014. I was required to complete a 24-hour urine sample the previous day and a spot urine sample to take with me for testing. After my consultation I had a blood sample taken. I also had a kidney ultrasound in January 2015. A letter from Dr Daryanani confirming the investigations undertaken and noting, 'the cause of hyponatraemia whatever it is, should be made clear by these studies but at this moment in time the level at which sodium levels is, is of no major alarm **WITN1990007**. If it turns out she has dilutional hyponatraemia, we will

consider her for water restriction. This may of course be secondary to SIADH due to the Modafinil, Cipramil or even the previous Ribavirin for Hep C.' **WITN1990008** is the follow up letter from Dr Daryanani from February 2015 confirming 'the diagnosis of hyponatraemia either lies between drug induced SIADH or polydipsia. Having had a second opinion from the Clinical Biochemist [...] we suggest a trial of water restriction'. A further letter from Dr Daryanani from June 2016 noting he is referring me for a neurological opinion at the Walton as there is no obvious renal cause for the hyponatraemia **WITN1990009**.

42. Although my scalp psoriasis has cleared up after treatment, I still have skin problems with bouts of rosacea on my face and persistent reoccurring boils.

43. After an x-ray in 2008, I was diagnosed with osteoporosis. I struggle with pain in my hands, knees and right hip. I continue to take Codeine Phosphate 30mg and Dihydrocodeine 30mg on more painful days. I have crushing pains in my hands during some nights and severe numbness. The pins and needles in my hands can last up to one hour after getting up and on and off during the day when I am tired or have used my hands for too long a period, such as typing or writing.

44. After having three rounds of treatment for HCV, I struggle with increased muscle and joint aches and pains and my hands and feet joints have developed hard, raised lumps which, Dr Alam advised, is a visual sign of progressive osteoarthritis and early onset arthritis, possibly triggered by the adverse effects of Interferon or Ribavirin treatment.

45. The specialist nurse at the gastroenterology clinic at the Royal Liverpool Hospital advised at the start of my courses of treatments with Ribavirin to take extra care of my teeth and gums. This is because Ribavirin can reduce bone density and cause premature gum shrinkage. After completing several rounds of treatment with Ribavirin I fear it may have caused the many problems with my teeth and gums that I now have. I developed a gap between my upper

front teeth, gum shrinkage and my upper left front tooth became very loose and I had to have it removed and replaced with a denture. I have had two further extractions, one of which was by an orthodontist at Arrow Park Hospital, Wirral, and the orthodontist advised me that I now have gum disease. In June 2019, my dentist advised me that I have a number of loose teeth which may need to be removed over time. However, he made a care and treatment plan for me to have regular dental cleaning visits, examinations and to only extract loose teeth individually over time.

46. I continue to suffer a range of debilitating symptoms which include hypersomnolence, myoclonic uncontrollable muscle jerks, spasms, tremors and muscle discomfort. I also struggle with episodes of sudden, painful heavy feelings or hollow empty sensations and loss of power in my thigh muscles. My legs feel like jelly and I shuffle or drag my feet when I walk. This happens at home and sometimes when I'm out walking or shopping, making it harder to keep my balance, walk without veering to the left or right, or knocking into people or things. On one occasion, while standing at a pharmacy counter, my thigh muscles suddenly lost power, felt hollow and I dropped to the floor. I was assisted to a chair and, after a short rest, I regained feeling and strength to my thigh muscles and was stable enough to stand up again.

47. Because my symptoms are sudden and change in combination and severity, my day to day activities are limited, which makes it frustrating and difficult for me to plan ahead, make appointments in advance or make arrangements to spend time with family and friends.

48. I remain under the care of my neurologist, Dr Aji, for follow up consultations, close monitoring, treatments and ongoing tests every six months. I was referred by Dr Aji to Aintree Sleep Studies Clinic for further tests under a consultant, Dr S. Craig. A letter from Dr Aji to my GP dated July 2015 noting that I had 'functional movement disorder' **WITN1990010**. A further letter from Dr Aji to my GP dated 8 January 2017 noting my MRI result and incidental CSF oligoclonal band positive **WITN1990011**. The letters note I do not exhibit

any clinical features of demyelination, the MRI shows no changes consistent with demyelination or inflammatory in nature, though there is small vessel ischaemia, and Dr Aji says, 'she has also been noted to have long standing diagnosis of hepatitis C and I just wonder whether the CSF oligoclonal band is a cross reactive or false positive'. A further letter from Dr Aji dated April 2018 diagnosing Episodic Functional Neurological Weakness (a result of a problem with the functioning of the nervous symptoms where the brain fails to send or receive messages correctly) noting that, 'she has been investigated extensively and all the investigations came back normal apart from non-specific positive CSF oligoclonal bands. I explained to her that these episodes she describes sound like a functional weakness as she is aware and can communicate during these episodes. I explained to her that there is no definitive treatment, other than trying to desensitize these episodes or for them to understand the condition and manage it better.' **WITN1990012**

49. Following my initial consultation with Dr Craig it was arranged for me to attend three separate admissions to Aintree Hospital Sleep Lab Ward, for a 24-hour sleep studies tests. Dr Aji booked me for a lumbar puncture, blood test and MRI Scan. I remain under Dr Craig's care for follow up consultations every 12 months, close monitoring and ongoing tests as required.

50. I believe my infected status may have impacted on my treatment for other conditions as follows. On 23 February 2012 I had an ultrasound and the SpR in gastroenterology, Dr Asimina Gaglia, sent a letter dated 27 February 2012 to my GP (**WITN1990013**): 'Mrs Taylor has a recent diagnosis of small bowel Crohn's disease. [...] the disease in the terminal ileum was 20cm in length with pre-steroidic dilation and second 5cm stricture in the distal ileum. There is no sign of an abscess but there is a possible fistula between the sigmoid and the distal ileal lip. The decision was to do a colonoscopy as she has not had the full colonoscopy before to assess if there is colonic Crohn's and to look for a fistula in the sigmoid. She will see Miss Nicol colorectal surgeon in clinic for surgical intervention to be arranged.' I do not recall these results being

brought to my attention or discussed with me, or having any further investigations or tests as advised in the letter. However, as it was in February 2012, when I started my last 12 months combination treatment with pegylated Interferon and Ribavirin, it's highly possible that my HCV was prioritised as a greater need and important to be treated first.

51. Since my diagnosis of small bowel Crohn's disease in 2012 following a compacted bowel my GP decided to refer me for further investigation early this year. I am currently being treated by my GP with a combination of medications for a compacted bowel. I have been referred to the Gastroenterology Department, Arrow Park Hospital, Wirral for further investigation, tests and treatment. I received a referral letter on 3 June 2019 and advised that I will be contacted as soon as an appointment becomes available.

Medical records

52. I have been unable to gain access to all my medical records. Due to the closure of Freedom Fields Hospital in 1998, a percentage of my medical records are missing or have been destroyed.

Impact of the Infection

53. The impact of being infected with HCV has had a profound effect on my private life and marriage.

54. Shortly after my husband had passed his commercial pilot studies and training, I became very unwell and was diagnosed with HCV for the first time and we had to return to the UK for me to receive treatment. It was a very painful time for us both and my husband had to cut short his course studies and lifelong dream to become an airline pilot.

55. My family and friends have given me a lot of love, care and offers of help over the years. However, there have been times when I have not always felt well

enough to be with them and have had to turn down invitations to get together. However, there have been times when I have not always received the support or understanding which I needed. I have also felt guilty when my ill health has meant I have been unable to do things with my grandchildren and I have had to disappoint them.

56. I had to stop work in 2011 shortly after we returned from Australia to the UK due to being diagnosed with my second relapse with HCV. Not working creating huge financial worries and, whilst I started my third course of 12-months of combination treatment, my husband had to take the financial strain by increasing his work load.

57. The saddest and most difficult impact of my triple HCV infections has been not having had a child of our own. This is because my first relapse was within a short time after completing my initial Interferon treatment and, after completing treatment for my second relapse, I was 49 years old and my husband, 60. GRO-C GRO-C GRO-C Although I have been lucky to have a good relationship with my step daughter and two step grandchildren, whom I love very much, it can never be the same as having your own child or children.

Section 6. Treatment/Care/Support

58. I was offered no counselling or psychological support in consequence of being infected with HCV or following the two further relapses. However, I would have liked to have been offered some support, especially when I was suffering from severe depression during my first six months Interferon Alpha treatment.

59. Because of my depression during, and for a prolonged period after, treatment, my specialists Dr Lombard and Dr Smart at the Royal Liverpool Hospital decided to start me on Cipramil (20mg tablets) antidepressant medication six weeks prior to commencing my second and third round of HCV treatment. A letter dated 31 March 2016 from Dr Craig, Consultant Respiratory Physician,

which states, 'she has had bouts of depression often associated with the interferon therapy for the past 15 years, and each time she was started on antidepressants'. **WITN1990014**

Section 7. Financial Assistance

60. I registered with the Skipton Fund and applied for the Stage 1 payment in August 2017. I received a lump sum payment of £20,000 in October 2017 and I received a separate winter fuel payment of £505.00 in December 2017. **WITN1990015** is the Skipton Fund application.

61. From April 2017 to 31 March 2018 I was entitled to receive Stage 1 regular monthly payments of £252.50. After the Department of Health confirmed a 1% increase from April 2018-2019 I received monthly payments of £333.37 and a winter fuel payment of £519.00 in December 2018.

62. In July 2018 I was eligible for and received the EIBSS top-up income payments of £362.00 per month.

63. I was advised to apply for the Stage 2 (EIBSS) Special Category Mechanism and I began receiving these monthly payments of £1,500.00 on the 27th of each month from December 2018 onwards.

64. I find it difficult to put into words how much these payments have helped to ease the worry and stress of being on a low income.

Section 8. Other Issues

65. Although I am a strong, positive and determined person, I still find it difficult to accept the fact that my life could have been very different without HCV.

66. I am blessed to have a wonderful, understanding and supportive husband, who has been right by my side every step of the way, I have such loving parents

who have supported me throughout and came with us for my first liver biopsy at Kings College, London.

67. After being initially diagnosed with HCV and having two further relapses, due to treatment failure, it is hard to predict what the future holds in terms of my health.

Statement of Truth

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

Signed GRO-C

Dated ...10 December 2019.....