Witness Name: Mark Bray
Statement No.: WITN3692001
Exhibits: WITN3692002- WITN3692008
Dated: 30 September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARK ROBERT BRAY

Section 1. Introduction

1. My name is Mark Bray and my date of birth is GRO-C 1955. My address is known to the Inquiry.

2. I have one brother who has died and one sister, Kim Oakley, who has also submitted a written statement to the Inquiry. I have four adult children; three sons and a daughter. I live with my partner in GRO-C.

Section 2. How Affected

3. I am writing this statement on behalf of my late mother Mary Violet Bray, who was infected with Hepatitis C (HCV) from a blood transfusion she received during a hysterectomy in the late 1960s or early 1970s.

4. Early on the morning of 17th May 2019, my world came crashing down, when I heard from my sister Kim that our mum was part of the Infected Blood Inquiry ("IBI") which had just started. It shocked me to the core and I have struggled to come to terms with the situation ever since, especially in light of the fact that I too contracted HCV, and at the time there was never a clear explanation from the doctors as to how I contracted it.

5. Although it was never clear to me how my mum contracted HCV, it had never occurred to me (or I believe, her) that she had received contaminated blood products and, I suppose that as a boy, growing up in the 50s/60s, it was not something that my mum would ever have discussed with me. So, as you can imagine, the communication from my sister was indeed a massive shock.

6. I believe that my sister has provided the information relating to my mum's diagnosis and how the disease progressed and so I will focus this witness statement on the facts relating to the time around Easter 1990 just before my mother died.

Section 3. Other Infections

7. Please see the witness statement of my sister Kim Oakley for further details.

Section 4. Consent

8. Please see the witness statement of my sister Kim Oakley for further details.

Section 5. Impact

9. One day around Easter in 1990, having returned home from work early, I called my mum for a chat and to check that she was okay, especially as she had been out for the day with my first wife and our children (from that marriage), visiting HMS Belfast. She had been feeling very tired over the previous few weeks and I was concerned about her as the yellow tinge to her skin had worsened.

10. On calling my mum, it was clear that she was not very well. It took her an age to answer the phone and when she finally did, Mum admitted that she had started to cough up some blood and I told her that my wife at the time, Sally Ann (who was also at home) and I would come straight away and take her to St Mary's Hospital at Roehampton, where she was being treated for her liver condition. The treatment was in the form of medication (I do not know what medication) to try and manage her condition as at that time there did not appear to be a cure. From my understanding, the cocktail of drugs that she was taking, although were apparently slowing down the deterioration of her liver, they created other health problems. We drove from our home in GRO-C Surrey to GRO-C as quickly as possible and took my mum to the hospital. Sally Ann drove the car and I sat in the back taking care of Mum. During the journey Mum continued to cough up significant amounts of blood, which got on me as I tried to help her. I work in construction and had uncovered cuts and scratches on my hands. It never occurred to me at the time that I was at risk of infection. Our main concern was the care of my mother.

11. On arrival at St Mary's, Mum was taken in to see a doctor straight away, and I contacted my father to let him know where we were so he could come straight from work to the hospital. After a few hours, the doctors confirmed that mum would be staying in hospital and that they had made

her comfortable and were just waiting for a bed for her. Dad said he would stay with her and that my wife and I should go home. He would let us know if anything changed.

12. It wasn't until the next afternoon, when my sister managed to contact my wife, that I heard that things had gone drastically downhill for Mum and that she had had a massive oesophageal bleed as a result of varices. This was a surprise for me and my wife as we had never heard of the condition.

13. I rushed back to St Mary's as quickly as I could to find my mum had been moved to ICU and was now in a medically induced coma whilst the medical staff tried to get the situation under control. My dad was distraught and unable to think clearly and it was clear that he would need a lot of support during this process, however long it was going to be.

14. Over the next few days it was evident that things were not improving. The medical staff at St Mary's decided to move Mum to St George's where it was felt that they were better equipped to deal with any eventuality. On the day before Mum was moved, my wife and I visited her at St Mary's and I vividly remember saying to my wife as we left the hospital some time later that I thought things were not looking good and that she was going to die. My actual words were "She's not going to come out of here".

15. On transfer to St Georges on 3rd May 1990, the doctors tried to give us some encouragement that mum might rally and start to recover. Mum underwent a couple of further operations, in an attempt to get her to a position whereby her condition might improve. Eventually, the doctors felt that she was strong enough to be taken off the medication and bought back into consciousness; however, she needed a tracheotomy before that process could be started. The tracheotomy was performed and Mum was gradually weaned off the medication which was keeping her sedated.

16. The previous weeks, watching her lying there in a coma, was harrowing but that was nothing compared to what happened once she had regained consciousness. It was very difficult indeed to sit and watch her become aware of her surroundings and get some understanding of what had happened. What was even more difficult was that because of the tracheotomy she was unable to speak and so communicated by mouthing what she wanted to say.

17. After two or three days of consciousness, whilst I was visiting her late one evening, she mouthed that she wanted me to take her home. I told her that I couldn't take her home as she wasn't well enough and that she would not survive. Her response was "I know .... Please take me home". Words cannot express how I felt at that moment – I do not have the vocabulary to explain, to say that I was devastated is a huge understatement. Even now, not a day goes by without me closing my eyes and seeing my mum.

18. I knew then that my mum was going to die and a couple of days later, whilst visiting her, the doctors came to talk to me and confirmed that there was nothing more that they could do and so they wanted me to make a decision about turning off the life support. I told the doctors that this was not a decision for me to make, and that I would have to get in contact with my dad. I phoned my dad and had to explain to him that he needed to come back to the hospital to have the conversation with the doctors. Once the decision had been made, the machines were turned off and mum passed away on 25th May, 1990.

19. I knew I had to be strong for my dad and the rest of the family and so I hid my emotions as deep as possible and tried to do everything that my dad needed. I don't think I have ever properly grieved the loss of Mum. She was such a major influence on my life and I have always found it very difficult to deal with her loss. I don't think any of the family dealt with her death very well as she was obviously taken well before her time and I

think this contributed to the break up of the family. Even today, nearly 30 years after her death, I find it very difficult to have to recall the events and put my thoughts down on paper.

20. As my sister mentioned, my mum was the centre piece of the family, and everybody came together because of mum. After her death the family fractured and was never the same again. My mum was my rock and always the person I turned to in times of crisis. I know that I disappointed her several times as a result of my life choices, but she was always there for me. After her death, I felt lost and found it hard to communicate those around me and I largely lost contact with my brother and sister. I had not been especially close to them anyway but not having my mum around meant that we had less and less reason to come together and so I rarely saw them.

21. My relationship with my father has also been troubled since my mum died. My dad relied on my mum for everything; she always handled the money, and looked after the household and children. I was the oldest child, so after mum died my dad and I got closer at first as I supported him with these things. After the first few years, however, he started to deteriorate because my mum wasn't there, and our relationship suffered. For the last five years of his life I didn't really speak to him.

22. My maternal aunt still does not know that my mum had HCV. I am not sure how much my mum shared with her over the years, although I do remember that my aunt was always saying that my mum shouldn't have had so many blood transfusions. She is 81 now and I do feel I need to tell her that my mum was infected with HCV from a blood transfusion and that was the cause of her illness; however I know this will upset her so I need to find the right time to do so.

23. This statement is not about me but about my mum and the impact on the family, and as such I don't think it would be complete without setting out below my own diagnosis with HCV.

24. In 1992, my wife gave birth to our daughter, Polly. GRO-C GRO-C GRO-C my wife decided that she did not want any more children and she asked me to have a vasectomy. I was reluctant to go through with the procedure but after much discussion, lasting a couple of years, I finally agreed.

25. In February 1997 I visited our GP, Dr Ko (in Wallington) and discussed the process with him. He suggested that before he started the process, that he should take a full blood screening to make sure that I was fit and well and that there were no underlying issues which might indicate that I should not continue with the vasectomy. On getting the results of the blood test, Dr Ko informed my wife and I that the liver function indicators in my blood test were not within the normal range and he therefore wanted to test further to see what might be wrong.

26. On 8 April 1997 Dr Ko referred me for testing at St Anthony's Hospital. In his referral letter he wrote the following **(WITN3692002)**:

"His mother had a history of liver problem, probably cirrhosis and had treatment under King's. He is on Morten 4 mg od for his BP and it has come down to 140/95 when I saw him last time in March. He used to drink considerable amount of alcohol and denied drinking at present".

27. The consultant responded to Dr Ko on 29 April as follows **(WITN3692003)**:

You presented an interesting problem with Mark Bray, who is a pleasant 41 year old man who works as a steel erector, does not drink on duty and really does not drink excessively at all. In the past he certainly was addicted to Bacchus but has an interesting collection of liver function tests, with a sharp rise in the ALT from 174 to 277. His gamma GT is in the same kind of range, which suggests this is not a drug or alcohol *problem. Certainly, his alcohol intake at present would not, in any way, explain these figures. The most interesting aspect was the death certificate of his mother, who suffered from chronic active hepatitis.*

He went on to confirm that I would he tested for Hepatitis A and B, and Hepatitis C if those were both negative.

28. A few weeks later, Dr Ko informed us that I had HCV. He questioned my lifestyle and having always been honest and open with all doctors, I mentioned that I had drank alcohol and had two tattoos when I was a teenager, as well as GRO-C. Dr Ko then made, in my opinion, an uninformed decision that GRO-C was how I had contracted HCV. I had had full blood screenings before and nothing untoward had shown up in the results, and in addition, I believe I would have noticed symptoms earlier and my liver damage would have been much more serious by then if I had contracted the disease such a long time ago. However, Dr Ko latched on to my teenage experimentation and did not want to listen to any other reason for my infection. He totally discounted the fact that my mother had had HCV and had died recently as a result, and that I had handled significant quantities of her blood while caring for her toward the end of her life. We explained what had happened to my mum at the time when she was coughing up blood but again he discounted that as a reason for my contracting HCV.

29. Through my wife's private health insurance with BUPA, from her employer, I was referred to Dr John O'Grady, Consultant Hepatologist at Kings College. The referral letter notes that my mother had "chronic active hepatitis, type unspecified". **(WITN3692004.)** After my consultation, my consultant hepatologist sent a letter to Dr Ko which notes my history as follows **(WITN3692005)**:

"He had tattoos fashioned approximately thirty years ago. GRO-C GRO-C *between the ages of 16 and 17. He has had*

no transfusions. He does not smoke cigarettes and describes himself as a moderate consumer of alcohol. He works as a steel erector. He is currently married for three years and has had four children by three separate partners. His mother died from liver disease at the age 57 but he is not aware of the precise diagnosis."

He also noted that "the appearances on liver biopsy indicate that a course of Interferon is recommended. I will see him in the near future to discuss the implications of this with him" **(WITN3692005).**

30. When I met with Mr O'Grady, he confirmed that I had HCV and stated that 80% of people who contracted HCV would never pass it on to others, but the remaining 20% could pass the disease on. Following rigorous testing, including my first liver biopsy, he confirmed that unfortunately I fell into the 20% category. He gave my wife and I clear instructions on how to minimise the risk of passing on the infection (not sharing towels, toothbrushes etc. and ensuring that if I was to cut myself, anybody treating me be informed and be advised to wear protective gloves.). Mr O'Grady also explained to me that the biopsy had shown that my liver was "bright".

31. I am grateful that Mr O'Grady gave me information about how to avoid passing the virus to others. It occurs to me that my mum did not receive any information about this, so would not have known to tell me to take precautions while handling her blood when she was ill.

32. Mr O'Grady then confirmed that there was only one treatment available to me, which was interferon treatment. He said that the same test that confirmed I fell into the 20% category of infecting others also had shown that the chance of getting a positive result from interferon treatment was minimal.

33. However, it was worth a try and I started on a treatment of Interferon, injecting myself daily. The initial treatment was for 6 months with testing

after 3 months. It was explained to me that if there was no improvement shown at the 3 months stage, then it would not work and so the treatment would discontinue at that stage. At the 3 month stage, I was tested again, and was still found to be positive with no signs of improvement and was therefore transferred into a maintenance mode.

34. BUPA were unwilling to continue to pay for private treatment for what they considered to be a chronic illness with an extremely slim chance of a cure, so Mr O'Grady transferred me into his NHS clinic and I started a pattern of six-monthly check-ups and a liver biopsy every couple of years. I was registered under the care of Specialist Nurse Katherine Barry.

35. I continued to attend King's College Hospital for several years on a regular basis and the HCV continued to progress. After the 2001 biopsy, my consultant stated that I did not need anti-viral treatment for my Hepatitis C as there was no liver disease progression compared to the biopsy in 1997. **(WITN3692006).**

36. However after the liver biopsy of 2005 the level of fibrosis had reached level 5/6 (early cirrhotic transformation). **(WITN3692007).** In February 2006, we were advised that there was a 'new' treatment that I could try which was a combination of Pegylated Interferon and Ribavirin. By this time my HCV had progressed and the latest liver biopsy was showing Stage 5 (out of 6) fibrosis, genotype 2B. By that time I had also developed chest pain which needed to be investigated before I would start the treatment as there was a risk in having the treatment if I had significant coronary artery disease as the treatment would lower my Hb levels. Following an angiogram, I was cleared for the treatment which was started towards the end of 2006.

37. It should be noted at this point that the 'new' treatment of which I was advised in February 2006, have in fact been available for 2 years. When we questioned Nurse Barry as to why the hospital had not offered me the treatment sooner, the response was that "they had offered it to new

patients first". Both myself and my wife were furious that given my HCV and the condition of my liver I had been allowed to deteriorate for a further 2 years before being offered the treatment. It seems illogical to me that I was not offered the treatment earlier and in 2006 the condition of my liver was such that I believe it would have been most advantageous to treat me sooner rather than later. I felt very let down by the lack of joined up thinking but was determined not to let that affect me as I went through the treatment.

38. The course of treatment was for 24 weeks and at the end of that treatment in May 2007, I was informed that it had been successful and I was now clear of HCV. **(WITN3692008).** I was then recommended for follow up ultrasound screening every six months for hepatocellular carcinoma. At that point, since I was now living in GRO-C I asked to be transferred to the local hospital, GRO-C, for any follow up appointments and I continue to be regularly checked.

39. The 10 years from contracting HCV to getting the all clear has taken its toll on both myself and my now ex-wife and whilst I am obviously delighted to have received the all clear, I can only wonder whether there might have been less impact on my liver if I have been offered the combined Pegylated Interferon/Ribavirin treatment two years earlier when it was first available and there might not have been an additional delay in starting the treatment due to the development of chest pain. I shall obviously never know.

40. I have felt generally unwell and tired over the years, but cannot think of any other particular physical effect of the HCV other than the deterioration of my liver, and the side effects I experienced from the treatment.

41. I feel that the emotional impact of having HCV has been less significant than the impact of my mother's illness and death. At the time of my diagnosis I didn't know that my mother had been infected, so I didn't

make the connection between the two. I simply got on with my work and had my treatment and luckily was able to clear the virus. Now that I know about my mother's infection I find it harder emotionally to speak about my own infection because it reminds me of what happened to my mum. Because she was infected earlier than I was, she had to suffer terribly whereas I was able to clear the virus and move on with my life.

42. I'm not very good with handling my emotions and I believe that I buried any emotion I might have felt about receiving the same diagnosis as my mother very deep so that I did not have to deal with it and so I withdrew slightly from my wife and daughter. I concentrated very hard on not letting the HCV interfere with my day to day life. However, in hindsight, it is clear to see that by doing what I did I had an adverse effect on my marriage and whilst my wife continued to support me 100% throughout the period from my diagnosis through the treatments and up to receiving the all clear, there were lots of things we no longer discussed and as a result the distance grew.

43. When the first treatment failed, both my wife and I knew that unless new treatments became available during the coming few years, my condition would continue to deteriorate and eventually I could potentially die. We never openly discussed that outcome and I skirted around the topic as much as I could and over the years it just became an unspoken fact, hovering in the background. Looking back I can see now that this must have taken its toll on my wife. After the first round of treatment I know that I became very selfish and lived my life in the way I wanted, with no real regard for my wife and daughter. We struggled on through a few years with me living the life I wanted with little concern about whether that suited my wife. My wife had a very demanding job and between her job, looking after our daughter and trying to get to grips with what was happening to me, it definitely took its toll on her. Eventually, GRO-C GRO-C GRO-C we agreed that we needed a new

start and decided to move out of London and so moved to GRO-C in 2002, hoping that this move would be the boost we needed to reconnect and rebuild. Unfortunately, after an initial 'honeymoon' the move didn't really help and in fact, by the time I underwent the second round of treatment which resulted in an all clear, we were basically living separate lives. GRO-C
GRO-C
GRO-C We finally separated in 2011 and divorced in 2013.

44. I obviously can never be sure what might have happened in our relationship had I never been diagnosed with HCV but up until that point we were a very strong team and enjoyed each other's company enormously. The diagnosis definitely led to me withdrawing from the family to a certain extent and because I couldn't express my feelings (or even understand what they were) that created a rift that we were never able to heal. This is something I will always regret.

45. I am a very private person and rarely told anybody about my diagnosis and as a result I don't think I was impacted by any prejudice or stigma. Given that I work in construction, I obviously informed people at work but only on a need to know basis, on the rare occasion that I needed treatment for any cut.

46. I work full time in construction. Although at times I was struggling with symptoms and the effects of treatment, I am the sort of person who just gets on with things as a way of coping. Even though there were times when I did not feel particularly well, I continued to go to work in the belief that it would take my mind off my condition. I do not like to dwell and felt that staying at home would not be good for my mental health. As a result I have never taken any time off work.

47. The diagnosis therefore did not really affect the family finances. There was no uplift in my wife's BUPA premium. In fact, once the first treatment was unsuccessful BUPA refused to pay for any further treatment, deeming the condition to be chronic with little chance of a cure.

Section 6. Treatment/Care/Support

48. I am not aware if my mother received any support for her HCV.

49. Counselling was never offered at any time following my diagnosis with HCV or throughout my treatment. I don't believe that I was ever made aware that it might be available.

Section 7. Financial Assistance

50. I have not applied for any financial assistance in relation to my mother's HCV or my own.

51. I did not know my mother had contracted HCV from a blood transfusion until this May when my sister contacted me about participating in the Inquiry. In relation to my own diagnosis, nobody ever mentioned the possibility of financial assistance at any time following my diagnosis nor during my treatment. That being said, I doubt that I would have qualified since my wife earned a good salary.

Section 8. Other Issues

52. I would very much like to have some acknowledgement as to how my mum contracted HCV in the first instance. Somebody, somewhere must have known that the blood products being used for transfusion were, if not actually infected, then were not of a sufficient standard. Why was the blood not screened to confirm its quality before being used?

53. I would also like to know why nobody gave my mum or indeed advised the family as to the precautions that we should take in order to ensure that we did not become infected ourselves. It was known how HCV could be transmitted and I feel that the authorities were negligent in a) not confirming how my mum was contaminated in the first instance; and b) advice was not given on how to prevent contamination for family members and others coming into contact with an infected individual who was bleeding.

54. Having attended the IBI Public Inquiry on Thursday, 6th June, 2019, ironically D-Day, in the company of my sister, taking place at Fleetbank House in London and listening to the oral statement given by a mother and daughter and subsequently a report on the BBC News this week from the IBI in Leeds where someone had lost four siblings from HCV infected blood products, I realise that although my initial treatment did not work and there was a two year delay in being offered the second course of treatment, which was successful, I am one of the very few lucky ones to have had HCV and survived. My mother and countless others and god only knows how many, were not.

Statement of Truth

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

Signed **GRO-C**

Dated ……30 September 2019.