Witness Name: Jane Tibbutt
Statement No.: WITN0556001
Exhibits: WITN0556002 – WITN0556003
Dated: 9th October 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JANE TIBBUTT

I, **JANE TIBBUTT**, will say as follows:-

Section 1: Introduction

1. My name is Jane Tibbutt. My date of birth is GRO-C 1940. I reside at GRO-C GRO-C. I married my husband, Dr David Tibbutt, in 1966. I was a Sister at the Nuffield Orthopaedic Centre and Staff Nurse at the Radcliffe Infirmary, Oxford until my eldest son was born in 1968. I left nursing about July 1968 before we knew about Hepatitis C and HIV. I make this statement based on my recollection of events and with the benefit of my medical records from the Worcester Royal Infirmary. At the time of writing this statement I do not have access to my records from the Oxford Haemophilia Centre ("OHC") and John Radcliffe Hospital, Oxford.

2. I have two sisters and a brother. We had no confirmed family history of haemophilia until my brother was diagnosed with this condition. Sadly, my brother went transiently blind after a facial accident on the Isle of Wight, and he was diagnosed with haemophilia by Professor G Macfarlane at the OHC when we got

back from the Isle of Wight. My uncle has researched our family history and we may be distantly related to Queen Victoria which would also provide a link with haemophilia.

3. I was told that I could be a carrier of haemophilia. GRO-C GRO-C. My brother had three children; GRO-C GRO-C

Section 2: How Infected

4. As a haemophilia carrier, I have had bleeding into my knee joint spaces (haemarthrosis) for which I was treated. I do not need regular treatment. I have had appointments at the OHC for reviews, which continued occasionally after I moved to GRO-C. My brother was also a haemophiliac and received treatment. Treatment before Factor VIII would have been fresh frozen plasma, and later, Cryoprecipitate.

5. I had my first son in 1968 at the Radcliffe Infirmary, Oxford and following childbirth I had a post-partum haemorrhage. I was given Cryoprecipitate, which I remember being very cold. I saw the medical team defrosting it. I was not asked to give consent for the treatment or told about any risks; it was all done in an emergency. I made a good recovery afterwards and I do not recall there being any side effects. I also had a blood transfusion at this time.

6. I did not receive any further treatment until 1979, when I had a bleed into one knee. For the first time, I received Factor VIII treatment for this bleed. My Rheumatologist at Worcester Royal Infirmary obtained the Factor VIII and I was treated at home. I do not recall waiting long for the treatment.

7. In 1980 I underwent a synovectomy of my right wrist at Worcester Royal Infirmary. I had reached to pick something up and my thumb would not move. A tendon had ruptured and an Orthopaedic Surgeon, Mr J Guy, one of my husband's colleagues, completed the surgery within hours. My husband had asked whether I would need Factor VIII cover for the operation and I received the American Factor VIII "Armour".

8. My husband and I have obtained and reviewed my medical records from the Worcester Royal Infirmary and OHC. I am now aware that my liver function tests carried out at the OHC were transiently abnormal in 1979 and 1980. My AST was around 70 at this time, but I was not aware of this. My alkaline phosphatase was also abnormal, which suggested liver cell damage. Between 1988 and 1991 there was also a significant elevation of my liver function test results, but again I was not aware of that at the time. At the time, the blood test abnormalities were blamed on my rheumatoid arthritis medication. Hepatitis C was never mentioned as a potential rationale.

Diagnosis with Hepatitis C

9. I received a letter from Dr Giogrande at the OHC in August 1995 arranging an appointment to discuss blood test results. Dr Giogrande seemed puzzled whilst he was talking to me. He said something like *"oh, didn't you know you had Hepatitis C".* Dr Giogrande seemed shocked that I did not know. The doctors had known the result since 1992, as they had tested a stored blood sample taken in 1986. I suspect everybody thought somebody else had told me.

10. I was only told that I was infected with Hepatitis C; I was not given any advice. I do not recall being angry about the diagnosis; I accepted it. Dr Giogrande told me that 95% of all specimens tested that were in storage at the OHC were infected. So if you had been treated at the OHC, it was almost inevitable that you were infected with Hepatitis C.

11. I was then referred to the hepatologist at the John Radcliffe Hospital in Oxford, Dr Joan Trowell, and saw her at the OHC.

Section 3: Other Infections

12. I am not aware that I contracted any other infections through contaminated blood products, other than Hepatitis C.

Section 4: Consent

13. I did not formally consent to being treated with blood products for the knee bleed in 1979, as it was given in a semi emergency. For the synovectomy in 1980, it was considered by the haematology department that I needed Factor VIII cover for the operation, although I was not asked formally if I consented to that. I was told that I needed Factor VIII and I was given it. I accepted the fact that I needed it.

14. There did not seem to be a risk assessment involved in this, or an investigation of what my clotting levels were at the time. My Factor VIII levels have been as low as 17%, but they have also been as high as 30%. At 30% I may not have needed Factor VIII cover for the synovectomy, which would have reduced the risk of contracting Hepatitis C. I think the doctors' decision to give me Factor VIII could have been better thought through.

15. I was not aware that the blood sample taken in 1986 and stored at Oxford was being tested for Hepatitis C in 1992. I was not told that the blood was tested, nor the results from those tests, until 1995. As a nurse, I understand the necessity to store blood samples.

16. Although I am grateful they tested the blood from the stored sample, so that I knew I was infected, I believe I should have been told when the test results were returned, and not three years later. This meant, for three years, I could not take personal precautions to ensure I did not transmit the virus and I could not inform those who should have known about the diagnosis, for example, the dentist. Once I found out, I suddenly realised I had to tell people.

17. I am not aware that I was ever tested for HIV, and I have never been told that I was negative for HIV, but I am sure they must have tested the sample for HIV at the time.

Section 5: Impact

Physical impact and treatment

18. I had my first appointment with Dr Joan Trowell in January 1996 and then I saw her about annually thereafter. I was under the care of Dr Jane Collier following Dr Joan Trowell's retirement but cannot recall when this changed.

19. Treatment for Hepatitis C was first suggested to me in 1996. Dr Jane Collier informed me I had genotype 1B Hepatitis C. This was the most difficult to clear. I was told I could have treatment with Interferon and Ribavirin. There was a 20% chance of me clearing the virus with Interferon and Ribavirin but the side effects were significant and unpleasant.

20. At the time I was not feeling unwell, although I was tired. Dr Collier thought there might be a more effective medication in the future. I decided to wait for a different treatment regime to become available and Dr Collier agreed to review me regularly in the meantime.

21. By 2000 I was becoming concerned about the possible complications of Hepatitis C, such as cirrhosis. I knew it was a possible risk not to have the treatment and I

was concerned about the extent to which Hepatitis C would cause liver damage. At one stage, the doctors considered performing a transjugular liver biopsy to assess the inside of the liver, as this would be less risky than a transcutaneous approach from the outside. But this would still have been potentially dangerous given my low clotting levels and so I decided not to have one.

22. I had a CT Colonography on 26 August 2015 at the Worcester Royal Infirmary which in addition reported that there was no evidence of liver cirrhosis [WITN0556002]. Subsequently I had a fibroscan in 2016 which again confirmed there was no evidence of liver cirrhosis and my liver function tests results were not grossly abnormal either at this point. Had I wanted treatment at that stage, I believe I would have been towards the end of the list, as my condition was not as serious as other people's.

23. In September 2016, I attended an event in Oxford and suffered from haematuria. I thought it was best we went home and attended the Accident and Emergency department at the Worcester Royal Infirmary. I lost the ability to speak and so my husband, David, requested the doctors for a CT scan, which took place on 3 September 2016 and again on 5 September 2016. I was diagnosed with a left sided spontaneous subdural haematoma. I could not speak for two weeks.

24. I later found out that this was due to a medication interaction. I had developed paroxysmal atrial fibrillation ("PAF") (June 2014), an arrhythmia of my heart, and I had been prescribed Warfarin to prevent thrombi from forming. When Warfarin is prescribed, your INR levels in the blood must be monitored to ensure they are carefully controlled. My INR levels were well-controlled, but then the medication I took for my trigeminal neuralgia (Carbamazepine) was gradually reduced to nil. That medication reduced the effects of Warfarin, and so when it was stopped, the Warfarin was having too great an effect, and should have been reduced. My INR levels were too high. The doctors stopped my Warfarin during this episode,

pending a review by a stroke consultant, and subsequently, anti-coagulation was re-instated Apixaban.

25. I have never been sure whether the PAF was related to Hepatitis C, or whether I would have developed this condition anyway. There are in the medical journals publications about a probable link between atrial fibrillation and Hepatitis C (in a well-known American Medical Journal) [WITN0556003].

26. In August 2017 I had treatment for Hepatitis C with a Direct Acting Antiviral, possibly Ledipasvir and Sofosbuvir which was prescribed by the John Radcliffe Hospital in Oxford. I was told it cost £50,000 for this course of treatment. Within four or five weeks of starting treatment the virus had cleared. My ALT liver function tests had dramatically returned to normal within four weeks of treatment. They had gone from 60 to 25, and the normal range is between 20 and 40. During treatment I did not have any side effects at all and within weeks I could see a marked difference in my tiredness. After the full three months of treatment, the virus had cleared. My ALT liver function tests are now in the normal range and I have continued to see an improvement in my tiredness.

27. Initially, it was difficult to tell if the tiredness was due to rheumatoid arthritis (which was diagnosed when I was around 26 years old) or the Hepatitis C, but now that the virus has cleared, I feel so much better. In May 2019 I had a hysterectomy and I even recovered well after that.

28. At the time, between diagnosis and clearing the virus, I did not think I was unwell with Hepatitis C but looking back, I was. It might be that I could have done more had I not been infected with Hepatitis C. For example, I used to entertain and I did not want to do that anymore; that lasted for a long time.

Psychological impact

29. I do not think the diagnosis affected me too much psychologically. I just accepted it. Unfortunately, my family was affected by haemophilia, and so we took any consequences as a part of that. I had had worse things than Hepatitis C, that were more troubling to me, and I was not feeling unwell at the time.

30. There were times I was anxious about the diagnosis. I remember a friend once said to me *"Jane you've had an awful lot to put up with!"*. I do not dwell on it and I have learned to accept things.

Impact on Employment

31. I did not really work after my eldest son was born. A friend offered me some work looking after some flats, but it never really took off. Consequently, the diagnosis did not really have an impact on my employment.

Impact on family

32. I do not know how much this affected my eldest son. He has always accepted adverse circumstances well, and my infection does not seem to have impacted upon him. He has never said anything to me about the effect of my diagnosis on him, but as a nurse he must have worried about Hepatitis C. **GRO-C** **GRO-C**.

33. I have not found the diagnosis has impacted my marriage. We did become cautious about various things. If we had not been so secure in our marriage, perhaps it would have affected us more.

Impact on finances

34. There was a significant impact on our travel insurance premiums following my diagnosis. For example, prior to having cleared the virus, I was given a quote of £3,000 to cover a four to six weeks trip. I had to tick a box to say that I had Hepatitis C, even though I did not have any symptoms. I had a discussion with

the insurance company about the nature of the infection and the fact that I did not have overtly active Hepatitis, fibrosis or cirrhosis..

Difficulties and obstacles to treatment

35. I never had any difficulties in obtaining treatment. I recall that the John Radcliffe Hospital had to obtain authority and funding from the local Clinical Commissioning Group ("CCG") for the treatment for Hepatitis C. I know that they needed to ask the CCG but they could hardly refuse to treat me given the circumstances. I was told there were no others in the local area that required funding for Hepatitis C treatment. It made me wonder how many more people in the area had not been told they were infected.

Stigma

36. We did not experience any stigma from friends and family; I found everybody to be sympathetic. We are very open about the diagnosis and it comes up in conversation. Had I been diagnosed with HIV, that might have been different, although HIV is not more contagious than Hepatitis C.

37. I did not feel there was a stigma at the dentist, he wears gloves anyway. The nurses treating me knew that I had Hepatitis C and often they would refuse to put gloves on, as it is more difficult to find a vein in gloves. Ultimately, nurses should take care when dealing with bodily fluids like blood anyway.

Section 6: Treatment / Care / Support

38. I have been associated with the OHC for over 60 years and I also received some treatment at the John Radcliffe Hospital. I have been treated at the Worcester Royal Infirmary at times, in particular in the Accident and Emergency department, since we have moved into the Worcestershire area in 1976.

Psychological support

39. I was counselled in relation to the treatment for Hepatitis C prior to commencing the treatment regime. Other than this, I was not offered any psychological support with the diagnosis. However, Dr Joan Trowell was very helpful and spoke to me during our medical appointments. I am not sure I would have accepted counselling had it been offered to me, as I believe sometimes it can do more harm than good.

Section 7: Financial Assistance

40. I received financial assistance from the Skipton Fund which was very useful, as we also had some other family issues at the time that this helped with too. I received a lump sum of £20,000 at the beginning of the Skipton Fund, at least 10 years ago. We were told we were not eligible for the enhanced amount.

41. We were told about the Skipton Fund via The Haemophilia Society and we applied for financial assistance. Our application was supported by Dr Collier. There was no issue with our application and it went through quickly and easily.

42. We began to receive monthly payments in December 2016, which have recently been increased, and we have had winter fuel allowance too.

43. I feel very embarrassed at receiving any financial assistance. It is quite overwhelming the amount we are being given, and we are getting the lower amount. For those with no income, these payments are quite substantial.

Section 8: Other Issues

44. My mother was very involved in the Oxford Haemophilia Society and with the OHC. My mother was responsible for a lot of young people that wanted to be treated at the OHC; she would find them lodgings to enable them to receive care

in Oxford. Through her work at the Oxford Haemophilia Society, my mother knew a lot of haemophiliacs, many of whom have since sadly died.

45. Members of my family have also been infected through contaminated blood products. My brother was treated for his haemophilia in Newcastle. He contracted HIV and unfortunately died. Originally, his symptoms were put down to alcohol. He contracted a specific type of pneumonia, pneumocystis jiroveci pneumonia commonly known as PCP, which is often contracted by those with advanced HIV disease. I do not know if my brother's wife, who lives in Scotland, received financial assistance and I do not want to bring the issue up with her. Initially, I would say that I was more affected by my brother dying from HIV than I was by my own diagnosis with Hepatitis C.

46. GRO-C was given "Armour" American Factor VIII products and as a result he contracted Hepatitis C. He was one of the fortunate few whose virus spontaneously disappeared. He does not want to be involved with the Inquiry.

47. I have been quite horrified watching the testimony at the Inquiry to see how many families with haemophilia have been affected by contaminated blood products. There are many more people who are worse off than me and there is a wide spectrum of stories.

Statement of Truth

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

Signed ....GRO-C........................

Dated ....9th October 2019..................