Witness Name: Dr David Tibbutt
Statement No.: WITN0555001
Exhibits: WITN0555002-WITN555003
Dated: 9th October 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DR DAVID TIBBUTT

I, **DR DAVID TIBBUTT**, will say as follows:-

Section 1: Introduction

1. My name is Dr David Tibbutt. My date of birth is GRO-C 1941. I reside at GRO-C GRO-C. I married my wife, Jane Tibbutt, in 1966. Jane has also prepared a statement for the Inquiry in respect of her personal experiences of being infected with Hepatitis C through contaminated blood products [WITN0556001]. I am making this statement in respect of the effect of Jane's diagnosis upon me.

2. I qualified as a doctor in 1967 and I worked at the Radcliffe Infirmary and other Oxford Hospitals and the Worcester Royal Infirmary ("WRI"), specialising in General Medicine and Cardiology. Often this meant that Jane's doctors were my colleagues. I retired in 1998 from practice in the UK and thence to Uganda 1998 to 2001.

Section 2: How Affected

3. My recollection of events is very similar to Jane's. Jane is a carrier of haemophilia. We have two sons; GRO-C GRO-C.

4. Jane has had occasional bleeding into her joint spaces (knees), haemarthrosis, for which she was treated. She does not need regular treatment with blood products. Jane was, and still is, associated with the Oxford Haemophilia Centre ("OHC").

5. When Jane gave birth to our eldest son in 1968, she had a post-partum haemorrhage, for which she was given Cryoprecipitate and a blood transfusion. This was done in an emergency situation and I do not recall being asked about Jane's treatment. She recovered well afterwards.

6. Jane did not receive any further treatment until 1979, when she had a bleed in her knees. This was the first time she was treated with Factor VIII (except for the Cryoprecipitate in paragraph 5) and she was treated at home by her Rheumatologist, Dr Popert, on advice from the Haematology Department of the Worcester Royal Infirmary.

7. In 1980 Jane underwent a synovectomy on her right wrist at WRI. A tendon in her right wrist had ruptured. One of my orthopaedic work colleagues operated on her and he was able to get her into surgery very quickly. I asked the doctors whether Jane would need Factor VIII cover for the operation because of her tendency to a low Factor VIII level.

8. It helped that, because I was a doctor, I knew which questions to ask the experts. I expected the haematology department to do a risk assessment and consider whether Jane needed cover at the particular time. Jane's own Factor VIII levels

varied, and sometimes they were as low as 17%. This variance was important as it would depend on Jane's clotting levels whether or not she needed Factor VIII treatment. On this occasion, the haematology department informed us Jane needed Factor VIII cover before the surgery and she was given the American Factor VIII product, "Armour". We did not question their assessment. Although Jane was on the ward at the WRI, I administered her Factor VIII. The surgery was successful.

9. Jane and I have obtained and reviewed her medical records from the WRI and OHC. We have discovered that the liver function tests carried out at the OHC were transiently abnormal in 1979 and 1982-88. Jane's AST and alkaline phosphatase were abnormal at this time, which indicated liver cell damage, but neither Jane nor I were aware of this. Jane's liver function test results were also elevated throughout the period from 1988 to 1991. It would have been helpful for us to have known this at the time. Instead, when Jane would go to the doctors with any symptoms, the doctors would say they were being caused by the medication she needed to manage her rheumatoid arthritis.

Diagnosis with Hepatitis C

10. Jane received a letter from Dr Giogrande at the OHC in August 1995 arranging an appointment. Jane was informed during that appointment that she had Hepatitis C. Jane recalled that Dr Giogrande seemed puzzled whilst he was talking to her and he said something like *"oh, didn't you know you had Hepatitis C?"*.

11. We are aware that the doctors had known that Jane had contracted Hepatitis C from 1992, as they had tested a stored blood sample taken in 1986. This delay is concerning, and I expand upon this below. Jane was not given any advice about the diagnosis, particularly in relation to transmission to other people. We just accepted the diagnosis and continued with our lives. Dr Giogrande told us that 95% of all specimens tested that were in storage at the OHC were infected. I am

aware there are patterns in the diagnoses across the country, depending on which blood products were available, for example, a large number of patients in the Newcastle and Manchester areas contracted HIV.

12. Jane was referred to the hepatologist at the John Radcliffe Hospital ("John Radcliffe"), Dr Joan Trowell. Jane had her first appointment with Dr Trowell in January 1996. Dr Trowell was very good throughout and after Dr Trowell's retirement, Jane's care was transferred to Dr Jane Collier, also at John Radcliffe.

Section 3: Other Infections

13. We are not aware that Jane contracted any other infections through contaminated blood products, other than Hepatitis C. I recall that Jane had a vaccination for Hepatitis B whilst at the OHC, which was administered by Mary Fletcher, a research nurse. I recall that the vaccination was not effective, because Jane's antibodies did not go up. She does not have immunity to Hepatitis B.

Section 4: Consent

14. Jane was given Factor VIII in semi-emergency or emergency situations, where there was no choice and it was not discussed beforehand. For the synovectomy in 1980, as I have set out above, it was considered by the haematology department that Jane needed Factor VIII cover for the operation. We did not question this and we assumed the department had carried out an appropriate risk assessment. Perhaps the hospital's decision should have been better thought through.

15. Jane was not aware that the blood sample taken in 1986 and stored at Oxford was being tested for Hepatitis C in 1992. However, as a doctor I was aware that it was standard practice to store blood samples.

16. In August 2014, I was tested for Hepatitis C and found to be negative. This would have been after Jane was diagnosed in 1995. I requested this test; it was not as a result of a recommendation from a doctor.

Section 5: Impact

17. From my perspective, the delay of three years between testing in 1992 and informing us about Jane's diagnosis in 1995 is one of the biggest concerns. We were not able to take interpersonal precautions for those three years, which put us at risk of cross-infection. We would also have ensured we monitored Jane's liver function test results, and insisted on regular ultrasound liver scans, had we been made aware of her diagnosis.

Physical impact and treatment

18. Jane had annual routine appointments with Dr Trowell, and thereafter Dr Collier. Treatment for Jane's Hepatitis C was not offered until August 1995. We were told that Jane had contracted genotype 1B of the virus, the most difficult type of Hepatitis C to clear. The first treatment offered to Jane was Interferon and Ribavirin, but Jane decided not to have the treatment. because she had heard there were significant side effects and only a 20% chance of clearing the virus with this treatment. Once Jane had made her decision to wait for alternative treatment, which we hoped would be forthcoming, she was reviewed regularly by Dr Collier and we continued on with our lives.

19. In the period between being offered treatment with Interferon and Ribavirin in 1995, and Jane's treatment in 2017, Jane had regular reviews and scans. At the time of a CT colonography in August 2015 extra colonic findings included no evidence of liver cirrhosis. A fibroscan in 2016 confirmed there was no evidence of liver cirrhosis. Her liver function tests results were not abnormal either at this point.

20. Jane developed paroxysmal atrial fibrillation ("PAF") in June 2014, an arrhythmia in her heart, for which she was prescribed Warfarin. Patients taking Warfarin must be monitored carefully with blood tests to monitor their INR levels. Jane also had trigeminal neuralgia and took a drug called Carbamazepine for this condition. As a doctor, I am aware of the importance of drug interactions. Jane gradually reduced her Carbamazepine with the knowledge of her GP, however, doing so meant Jane's Warfarin was having too great an impact on her. Her INR levels rose, and her Warfarin dosage should have been reduced.

21. This led to an incident in September 2016 where I had to take Jane to the Accident and Emergency department at WRI with haematuria. I was also concerned that Jane lost the ability to speak and I insisted on a CT scan. The doctors completed two scans on 3 and 5 September 2016 and she was diagnosed with a left sided spontaneous subdural haematoma.

22. I believe Jane's PAF could have developed as a result of her contracting Hepatitis C. However, this is difficult to prove, because Jane developed PAF at an age where it does commonly begin. She continues to have episodes of PAF about 4-6 times a year. These are successfully managed with one-off doses of oral flecainide. Her Warfarin was replaced by Apixaban. I believe there needs to be more research undertaken to look for a link between PAF and Hepatitis C. There have been at least two papers published in medical journals in relation to the association of Hepatitis C and PAF, which I have exhibited to this witness statement [WITN0555002 and WITN0555003]. I am aware that a number of conditions have been referred to in evidence to the Inquiry and I hope that, through this Inquiry, somebody begins to consider whether certain conditions could be exacerbated by, or linked to, Hepatitis C.

23. Jane was offered treatment with Direct Acting Antivirals for her Hepatitis C in August 2017. This treatment was provided by the John Radcliffe. Jane's ALT liver function tests rapidly returned to normal within four weeks of treatment. I do not

recall that she had any side effects from the treatment. After the full three months of treatment, it was confirmed that Jane had cleared the virus. Afterwards, Jane is far less tired. Her ALT liver function tests remain within the normal range.

24. It has recently become apparent that Jane has been developing a "glove" peripheral neuropathy of both hands. She has a changed sensation that makes tasks like doing up buttons difficult. It could well be that this is related to the Hepatitis C, and is being investigated by her GP.

Psychological impact

25. I do not think Jane's diagnosis has affected me psychologically; I am not psychologically disturbed by it. GRO-C had some problems; the difficulties he was going through bothered us more and the diagnosis paled into insignificance in comparison to that. In addition, I understood the virus, consequences and what to look out for.

Impact on family

26. We were very fortunate that we were secure in our marriage and so the diagnosis did not impact it. We accepted Jane's diagnosis. Our eldest son has never said anything to us about the impact of Jane's diagnosis, but as a nurse he must have understood the virus and the consequences. Our youngest son GRO-C GRO-C tends to be very "relaxed" about health issues, and we have not witnessed any adverse effects upon him.

Impact on finances

27. In terms of insurance, we have found that Jane's diagnosis with Hepatitis C has held us back. Our travel insurance premiums are higher as a result. For example, prior to Jane clearing the virus, we were given a quote of £3,000 for insurance to cover four to six week's travel. Insurance companies did not seem to understand the difference between just Hepatitis C infection and hepatitis.

Stigma

28. We did not experience any stigma from friends and family. We are very open about the diagnosis and it comes up in conversation. My work colleagues that had treated Jane would have known about her haemophilia, and later about her Hepatitis C diagnosis.

Section 6: Treatment / Care / Support

29. Jane has always been associated with the OHC and has also received treatment at the John Radcliffe and WRI, often from my work colleagues.

Psychological support

30. I was not offered any counselling in respect of Jane's diagnosis or during her treatment for Hepatitis C although Dr Joan Trowell did fully explain the possible outcomes. Jane received some counselling prior to beginning the treatment regime, but otherwise she was not offered any support.

Section 7: Financial Assistance

31. Jane and I received some financial assistance from the Skipton Fund which was very useful at the time. Jane received a tax-free lump sum payment of £20,000 from the Skipton Fund at least 10 years ago. We were told we were not eligible for the enhanced amount.

32. We were told about the Skipton Fund via the Haemophilia Society. We applied with the support of Dr Collier and the process was quick. We did not experience any difficulties during the process.

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

Section 8: Other Issues

34. I became President of the Oxford Haemophilia Society in 1974. I was introduced to this society because of Jane's family history of haemophilia. Her brother had haemophilia and has since died from HIV contracted through treatment with contaminated blood products. I was taught by Professor Gwyn Macfarlane, who was working with Dr Rosemary Biggs, both pioneers of the OHC. At the time Sir Weldon Dalrymple-Champneys was President of the national Haemophilia Society. I met a lot of haemophiliacs while I was in Oxford from 1960 to 1976. Unfortunately, a lot of those haemophiliacs I met have since sadly died.

35. As Jane has referred to in her statement, GRO-C was given "Armour" American Factor VIII products and as a result he contracted Hepatitis C, although fortunately his virus spontaneously disappeared. GRO-C does not want to be involved with the Inquiry.

Statement of Truth

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

Signed GRO-C

Dated 9th. October 2019