Witness Name: Mrs Wendy Campbell
Statement No.: WITN1848001
Exhibits: 0
Dated: 12 April 2019

INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF MRS WENDY CAMPBELL

Section 1. Introduction

1. My name is Mrs Wendy Campbell; my date of birth is GRO-C 1962. My address details are known to the Inquiry. I make this statement in memory of my late partner Mr Peter Lloyd. I live at the same address that Peter and I lived at when he was alive and we were together.

2. Peter Lloyd; who was my live-in partner for 12 years from November 1996, was born on GRO-C 1952. He joined the Royal Air Force (RAF) in October 1969 and left it on 29 October 1992. He enjoyed a very successful 22 year career in the RAF. He worked mostly overseas and had postings in Gan, Belize, Germany, Norway, Washington DC and Cyprus. Peter attained the rank of Chief Technician in October 1988 and was a sergeant. He very much enjoyed his work. When Peter left the RAF, and I believe he left because he could not progress any further with his career there, he went to work for a company based in Cyprus called BANDAI which manufactured toys; he was Operations Manager.

Section 2. How Affected

3. Peter was infected with hepatitis C via a blood transfusion he received on 16 July 1985, three days after a road traffic accident which took place on 13 July 1985. I understand that Peter required the transfusion to manage the various fractures that he had sustained during the road traffic accident. The blood transfusion was given at Queen Elizabeth II Hospital in Welwyn Garden City, Hertfordshire. I believe David Williams was the consultant who was in charge of Peter's care.

4. Peter did not have a bleeding disorder.

5. I provided information about the transfusion, the date of it and the hospital where he received it above.

6. To the best of my knowledge Peter was not given any information or advice about the risk of being exposed to infection prior to receiving the blood transfusion. I understand he was unconscious in the days prior to and on the day of his blood transfusion.

7. I have included in this witness statement information from documentation that Peter gave to me which formed part of his War Pension Claim to the RAF. The War Pension Claim was not solely made because of his hepatitis C; it was also made as a result of his other conditions. IN any event, the documentation helps to understand Peter's experience with hepatitis C, particularly in relation to how and when he found out, what he was told, and how his virus and infection were managed. The documentation comprises the detail of various letters, correspondence and an opinion that have been typed up and merged into one document. I understand that the war pension staff created this document and presented it to the war pension panel and to Peter for the purposes of this claim. To the best of my knowledge it accurately represents

the position at the time. This document can be made available to the Inquiry if it would be of assistance.

8. From this war pension documentation it appears that Peter received a letter dated 6 November 1995 from the National Blood Transfusion Service which was delivered to him via RAF Personnel Headquarters. The War Pension Claim documentation indicates that the Blood Transfusion Service had discovered that the blood transfusion that he received in Welwyn Garden City in 1985 may have been carrying an infection known as hepatitis C which could have been passed onto him. The National Blood Transfusion Service indicated that they would like to see Peter to explain further the position and to take a blood sample for testing. The documentation indicates that the letter explained that the blood sample would show whether or not there was evidence of hepatitis C infection, that Peter and his doctor would be informed of the result and that Peter would be offered specialist medical care if the result was positive. Peter was invited to make a call to arrange an appointment to be seen and a number was provided for that purpose. The letter set out that hepatitis C was NOT related to HIV (the virus which causes AIDS). I should point out that I was initially unclear about why it was the RAF that informed and delivered the news of the potential infection to Peter in 1995 as Peter had left the RAF in 1992. I have since found a record which states that the National Blood Transfusion Service did not have access to Peter's current address or the name and address of his GP in 1995, so they forwarded correspondence to RAF Personnel Headquarters. It seems therefore that Peter was identified as infected with hepatitis C virus (HCV) as part of the national HCV Lookback exercise for transfusion recipients.

9. The documentation indicates that the National Blood Transfusion Service wrote to Peter's Commanding Officer, at The Princess Mary's Hospital Akrotiri (TPMH). It seems the letter was dated 14 December 1995 and to have stated that '*The transfusion service in the UK has been reviewing the records of previous donations from donors now found to be positive for evidence of*

hepatitis c virus. The Department of Health has decided that recipients of blood or blood components from these donors should be traced and offered counselling, testing and follow-up including treatment. Mr Peter Lloyd has been identified in this exercise as having received a presumed hepatitis c positive unit of blood on 16 July 1985 while under the care of Mr ----, Consultant Orthopaedic Surgeon at QEII Hospital, Welwyn Garden City'.

10. Further the documentation states '*Mr Lloyd has been informed and I have discussed the exercise, testing, possible results and possible sequelae of hepatitis C infection with him at some length on the telephone, but at this distance, I am unable to arrange testing of a blood sample. It has been recommended that testing for viral material by polymerase chain reaction (PCR) as well as tests for anti HCV should be performed and samples are being sent to designated reference laboratories within the UK. However, for the PCR result to be valid the test should be performed within a few hours of collection of the sample or the sample separated and frozen within those few hours. I am therefore writing to ask whether you would be able to help us by arranging for Mr Lloyd to be sampled and preferably for the sample to be tested locally. I am happy to contact Mr Lloyd to discuss any arrangements or for you to contact him directly. I am sending him a copy of this letter and also an information leaflet which you may also like to see. Thank you in anticipation of your help'.*

11. I have included the detail of the information leaflet below; it may be helpful to the Inquiry as it provides general information about hepatitis and blood donations, and testing for hepatitis c since 1991. The documentation states that '*Hepatitis literally means inflammation of the liver and this inflammation can be caused by many irritants, the commonest being alcohol. Some viruses are known to cause hepatitis. In an acute illness with such a virus the liver can show signs of severe inflammation which is detectable by blood tests. Most individuals who 'catch' any of the various forms of viral hepatitis recover completely. Some individuals, however, do not clear all the viral material from*

their body and they then become carriers of the infection. We know this to be so in HBV and HCV infection. Individuals who are carriers of these viruses usually feel completely well and are unaware of their condition. It is only by using very special tests that the carrier state can be revealed'.

12. The documentation indicates that a letter was sent to Peter from the Head Consultant in Transfusion Biology; it seems that the letter was dated 11 June 1996 and to have informed Peter that the blood sample he gave on 30 May 1996 was tested for evidence of hepatitis C infection and that the result was positive. The documentation informed Peter that he was a carrier of the virus and that further contact from him was awaited in order that contact could be made with his own doctor so that he could be referred to a liver specialist for further assessment. Peter appears to have been provided with the contact details for two doctors that he could contact, one for him to contact on his return to the UK and one for him to contact in the interim for further advice about the implications of his test results.

13. The information leaflet (as typed in the War Pension Claim documentation) states:

    a. '*Testing for HCV. Tests for HCV are relatively new and donated blood has been tested only since September 1991. Because the virus itself has not been isolated the tests rely on detecting antibody in the individual's blood. Antibody formation is the body's response to 'foreign' material and its presence is a signal that a particular individual has met the 'foreign' material at some point in the past. Many antibodies are protective and this mechanism is the basis of immunisation against infectious disease. In the case of HCV however, it appears that the antibody may not be protective but only be a signal of infection. As yet the tests we have available for HCV cannot say with any certainty whether an individual with antibody if* (sic) *infectious or immune and the latter state seems to be rare.*

b. *'Transmission. We know the hepatitis c virus is transmitted by blood and by sharing needles. These two routes seem to be the most efficient ways of passing the virus on to others. It is also possible that the virus can be transmitted by sexual intercourse although this seems to occur rarely. A person carrying the virus will thus need to consider informing his/her sexual partner, who may also wish to be tested. If the partner is negative for antibody to HCV then the use of condoms may be considered in order to protect the partner from the very small risk of infection with HCV. HCV is not transmitted by normal social contact or by sharing eating utensils.*

c. *"Illnesses. It is known that a small proportion of carriers of HCV go on to develop chronic liver disease, which may include cirrhosis. Extremely rarely liver tumours may develop. At present, very little is known about the long term effects of HCV. Also, because these conditions develop over a number of years, it is impossible to predict the outcome in any particular individual although additional tests at a specialist liver centre may give more information. We do know, however, that alcohol is an liver irritant and it is probably sensible for all hepatitis carrier* (sic) *to reduce or eliminate its consumption to avoid exacerbation of any ill effects of viral infection.*

d. *'Treatments. Treatments are being tried for carriers of hepatitis. Although none are completely satisfactory, some are helpful in a proportion of cases. There are a number of specialist centres dealing with hepatitis and it is in the individuals interest to be known at one of these. A full assessment can be performed there and useful treatment can be offered. Clearly one's own doctor should also be aware of the hepatitic c test result so that referral can be arranged. The Transfusion Centre will, with permission, pass our finding son* (sic) *to him/her. There is probably no indication to inform others apart from any sexual partner'.*

14. As a result of the War Pension Claim that Peter made, a medical opinion was provided by the Medical Division Department of Social Security, the documentation indicates that it was dated 19 March 1998. Peter would have been aware that: (see paragraph three) '*Hepatitis C is a flavivirus and its mode of transmission closely resembles Hepatitis B in that intimate personal contact and/or parenteral inoculation appear necessary. Incubation period is 5 – 10 weeks. Jaundice is rare and the disease is usually asymptomatic. Only 50% recover from hepatitis c infection and the remainder develop persistent viraemia (carrier state) and/or chronic hepatitis with one in five developing cirrhosis of the liver later. The course and eventual outcome vary in individual cases. However, they appear to be independent of external factors'.* At paragraph four: *'The evidence shows that the mode of transmission of the Hepatitis C virus in Mr. Lloyd's case was parenteral inoculation by transfusion of blood as part of the management of the multiple fractures that Mr. Lloyd sustained in a road traffic accident in 1985'.* At paragraph six: *'The evidence of the letter from the National Blood Transfusion Service dated 14 December 1995 and the attached information leaflet regarding Hepatitis C infection clearly shows that Mr. Lloyd's carrier state was diagnosed as a result of a review by the service of the records of previous donations since a test to detect the hepatitis c virus was introduced in 1991. As pointed out in the information leaflet quoted above and at paragraph 3 above, individuals who are infected with the hepatitis C virus are usually asymptomatic and unaware of the condition, with no overt disability'.*

15. In terms of how information about the infection was communicated to Peter, I feel it important to mention that Peter was told in around August/ September 2007 by St James' Hospital that his cirrhosis was in the centre part of his liver and an operation to remove the cirrhosis would not be possible. He was also told that he would not qualify for a liver transplant because he had hepatitis C. This effectively gave him his death sentence. At the time he was told he would have three to five years to live. Peter passed away only 10 months later, on 30 June 2008. I was devastated to hear this news. However, we both felt at that time we had a minimum of three years together which would give us time to

make plans. I remember that day clearly as we were en route to Peter's sister's 50th birthday party in Cardiff. He refused to change plans and made me swear not to mention what we had just been told. It became apparent the following year that Peter's condition was deteriorating quickly. We booked our wedding only three days before Peter passed away and bought matching wedding rings two days before. I have a vague memory of the nursing staff at the hospital offering to bring the chaplain to conduct a marriage blessing at Peter's bedside during the evening of 28 June 2008. I felt this was unfair as Peter was not able to communicate. A week later I had to go back to the shop to collect my resized ring and the staff said '*hope you have a lovely day*'. I feel totally cheated to have lost the man I loved who was only 55 years of age when he died. We should have had years together and he would have loved the fact his son and daughter would have given him another two granddaughters to adore.

29 Jun

Section 3. Other Infections

16. I do not know of any other infections that Peter received; to my knowledge he only contracted hepatitis C and he went onto develop colon and secondary liver cancer.

Section 4. Consent

17. Peter was unconscious at the time of the accident that led to the operation and the blood transfusions he received. He could not have consented to the treatment he received at that time. Peter gave his consent to being tested via a blood sample on 30 May 1996 for hepatitis C, sadly the result was positive. Peter was fully aware of the treatment that he was receiving for the hepatitis C, when he eventually received it. I therefore do not believe that Peter was treated or tested without his knowledge, without his consent, or with being given adequate or full information and I do not believe that he was tested or treated for the purposes of research.

18. It may be helpful to the Inquiry to know that it seems Peter consented to participate in two studies relating to his hepatitis C; one called the '*Trent Hepatitis C Study*' and one called the '*Innogenetics Study*'. I know nothing more about either of these studies.

Section 5. Impact

19. Peter was devastated to learn he had contracted hepatitis C. Eventually it was to have a profound emotional, psychological and physical effect on him.

20. At the time that he learned he was carrying the infection, which was in June 1996, he was living and working in Cyprus and in a very well paid and lucrative job. He was comfortable in his life. He had to give up his job and his life there and return to the UK to commence treatment for the hepatitis C. Up until the diagnosis, I was not aware of there being a physical or a mental impact of the infection on Peter. When Peter moved back to the UK in around November 1996 he started a car import business. This gave him focus around the hepatitis C and helped him initially to cope with the diagnosis. The records do help to understand what went on both before and after his diagnosis and report that some symptoms were present from as early as February 1997, when Peter was feeling quite unwell and very lethargic. Eventually and very sadly the car business ended up in liquidation in around 2002. I believe that the business failed in part, as a result of the amount of time Peter had to take off work to attend the appointments for the hepatitis C; these appointments were located in Leeds which was an hour and a half's drive away and so every time he had to attend he had to be away from work for a full day. The failure of the business caused enormous financial stress and pressure on Peter and on our day-to-day lives. Peter had invested everything into the business and had been propping it up with savings, so when it folded he had no reserve left. He ended up having to rely on disability money and his RAF pension. The business failing coincided with Peter feeling more profoundly the physical effects of the hepatitis C. Losing of the business served to remove purpose from Peter's life and change

his habits. He became lost in himself and felt he could not contribute. He started to sleep until lunch time and stayed awake until late. Peter started to become depressed and was drinking more as a result.

21. Following his diagnosis with hepatitis C, Peter developed diabetes with thirst and polyuria, he was also diagnosed with and ad a resection operation in February 2006 for colon cancer. The operation was successful and Peter ultimately achieved remission. It was on a follow up routine appointment in February 2007; when a blood test was completed, that we found out that the cancer had come back but that it was in his liver. In my view Peter's death certificate is not quite correct in that it states that he died as a result of *'I(a) Metastatic Colon Cancer'* and *'II Hepatitis C and Liver Cirrhosis'* because it does not reference the fact that he had developed and died from the liver cancer; particularly because he had achieved remission from the colon cancer.

22. Looking back on things now, it seems to me that Peter's condition quite rapidly deteriorated in the end. From being diagnosed with hepatitis C in June 1996, he was found to have Grade 1 Fibrosis in January 1998 and to have a score of 5 on the Knodell and 4 on the Ishak schemes. Peter went on to develop colon cancer; I am unsure when this diagnosis came about and although he achieved remission from it through a resection operation in 2007, he went on to develop cirrhosis of the liver and liver cancer. He died in June 2008. His records tell that his liver enzymes were elevated in a test undertaken in May 1996 and that at that time he appeared to have liver damage.

23. Peter's records indicate that from as early as December 1997, he was being considered for possible treatment for Interferon by St. James's Hospital in Leeds. A biopsy taken in January 1998 revealed that he had Grade 1 Fibrosis; the hospital considered that he was not a good candidate for Interferon therapy. They decided to keep things under review in clinic and planned to see him every six months with liver function tests and hepatitis C virus RNA estimation. The hospital team stated they would think about biopsying him again in 19

months to two years' time. The records suggest that Peter was lost to follow up until October 2002, following a chase from his GP. This was supposed to lead to another biopsy; however, the records do not appear to include the results so it is not clear whether he had one. It was in around March 2003 that it was noted that Peter's hepatitis C was genotype 3a. The hepatology department wrote that he therefore held the '*best chance of clearing the virus, probably in the order of 90%*'. It was decided at this point that Peter required six months of treatment, which the hospital considered was '*good news*'. Peter was commenced on treatment for Hepatitis C of Viraferon Peg 150mcgm prn giving 0.5mls and Ribavirin 600mg bd on the 23 May 2003. At this point he had been waiting for treatment for seven years, since diagnosis and his return to the UK for treatment for it. At the end of his treatment; the PCR test, the test to detect the presence of the hepatitis C virus in Peter's blood, was negative. The plan was for follow up three months later. In May 2004 Peter re-attended the liver clinic and had bloods taken for hepatitis C PCR. These tests came back positive; the hospital wrote that '*the hepatitis C virus has managed to evade treatment with the Interferon and Ribavirin*'. I am unsure as to what happened in the one year interim period. An appointment was made for November 2004, six months later, to follow up. There are no further records available to me which help to understand how his condition deteriorated and led to his death.

24. I do not know whether Peter experienced difficulties or obstacles in obtaining treatment. It is surprising to me that he did not begin treatment for his hepatitis C until May 2003, despite returning from Cyprus to access it in November 1996. Peter's records show that he was diagnosed with malignant ascites; liver metastases in June 2008. I cannot understand how his condition deteriorated to this point given he was told he had the genotype 3a and the best chance of survival (at 90 percent) and that he had previously tested negative to hepatitis C.

25. I do not know if there were treatments that were in the system that were not made available to Peter and which ought to have been made available to him.

It was known in May 2004 that his hepatitis C had circumvented the treatment interferon and ribavirin treatment that he had in 2003. He went on to develop liver cancer quite quickly thereafter and died in 2008. I expect that he should have received more or other treatment, which he did not receive.

26. Peter did not receive treatment until 2003. He developed severe flu-like symptoms, sickness, tiredness (most of the time) and lethargy, weakness, intermittent headaches, dry skin, and problems with his teeth (being sensitive to temperature). The fact that he was at home all day really bored and frustrated him and affected his mood even further. Following a review in February 2004, Peter was reported to be feeling very well now that the treatment had finished, but it was only a few months later; in May 2004, that it was confirmed that the virus had managed to bypass the treatment he had received.

27. I do not believe that his infected status impacted on his treatment, medical and/ or dental care for any other conditions.

28. The impact of this on Peter's private, family and social life was immense. Our relationship at times became very stressful due to the steroids and other medications that Peter had to take. Peter would very easily lose his temper over things that normally would not have bothered him. As Peter lost the business and had more time on his hands, he became more bored and would often sleep for much of the day, and then stay awake late at night and into the early morning playing online gambling games. He would spend huge amounts of money. When I tried to speak to him about it, he would get very defensive and say, '*it was his only pleasure*'. This added to an already difficult financial situation and put further strain on our relationship. I worked part-time up until 2003 when I had to return to work full-time. My full-time salary rose through promotion from approximately £11,500 to £17,000 in the year before Peter's death. During this time, it was my salary that was keeping us afloat. On the social side, Peter was often too tired to go out; however, on occasion when he and I did, I was concerned that too much alcohol would be consumed which

would serve to exacerbate his hepatitis C. I would mention my concern to him which would usually always cause a disagreement. I think it difficult for me to comment on the impact of this on his family life and I refer to the statement of Victoria Gleadhill-Brown who will provide an insight into this.

29. The whole of this experience caused me deep emotional distress. I watched a very healthy, fun, strong, caring man that I loved dearly, deteriorate in front of my eyes and lose interest in his life, through no fault of his own. Peter and I stopped going out, particularly through the periods of time when he was on treatment because he was not able to drink. This caused him a lot of grief because having a drink offered him an escape. Peter was a very sociable person and liked to enjoy a drink with his friends. The inability to do this on top of everything else coupled with the medication placed severe pressure on an already delicate person and situation. When Peter passed away my GP insisted on me taking a blood test to ensure the hepatitis C had not been passed onto me, which was very stressful as I was already having to cope with the sad loss of my partner. Thankfully the result was negative.

30. At the time of his diagnosis and up until Peter's death, people were not fully aware of what hepatitis C was and it was often confused with drug users. Peter felt uncomfortable about the stigma that attached to carrying the virus; therefore, it was only his immediate family that were aware of his condition. When Peter passed away the funeral directors refused to embalm him due to him having hepatitis C. This was deeply upsetting for all the family as once again it made it feel like it was a '*dirty*' disease. This was a horrendous situation for the family to have to deal with.

31. I understand that the impact on Peter's other family members was very great indeed. I feel Peter and his family have missed out on so much family life together; he was devoted to his granddaughter GRO-C who was only six at the time of his passing. Peter's son and daughter have both had another child each which he would have adored in the same way as he did GRO-C. He and they have missed out on so much.

32. There were work-related and financial effects of the infection on Peter's life and on my life.

33. Peter was infected with the virus in 1985 and was not formally diagnosed until 1996. At this point in time we moved from Cyprus where he had been living for many years back to England to receive treatment. The treatment did not come until 2003. The work-related effects were that he had to give up a very comfortable life-style in a country that he loved, in order to come back to England to receive treatment for hepatitis C which he did not receive for another seven years. In 1996 I was not aware of there being a physical impact of the virus on Peter but I understand from a review of his records that it was already quietly taking hold. I wonder now whether Peter's inability to get the car business up and running was as a result of a physical and mental weakness that might have been taking hold within him. The attendance at the appointments certainly meant that he was unable to give the business 100 percent of his time and they did have an effect on the success of the business but it is difficult to say with certainty that it was the hepatitis C that led to the failure of the business. I imagine it contributed to it. Following the failure of the business Peter did not work again and started to gamble very heavily. He wanted to go to Las Vegas and gamble. This resulted in arguments. I felt that we needed to save some of the money in case it was needed for emergencies. He managed to incur a significant debt as a result and this brought a huge financial strain to our lives. When he died he owned about £3 on his credit card. He was not in any debt when he passed away.

34. I was working part-time up until 2003; I had to return to work full-time in February 2003. My salary was £11,500 until around 2007 when it rose to £17,000 through promotion. Due to Peter's condition we could not afford to get insurance to cover the mortgage because there were very high premiums imposed as a result of his hepatitis C diagnosis. I am still, more than 10 years since Peter's death, paying off the mortgage on our home.

Section 6. Treatment/Care/Support

35. There was a very long delay in Peter receiving the treatment for the hepatitis C, as I have indicated above. Peter received Interferon and Ribavirin at St. James's Hospital in Leeds, which is where the majority of his treatment and appointments were (the hospital is over an hour's drive from our home). The treatment produced a PCR negative result six months after treatment; but only a few months later, the virus was reported to have evaded the treatment. Peter developed liver metastases in 2008, and died in June of the same year.

36. Peter was given psychological and counselling support, which I believe he found helpful but I have never been offered psychological or counselling support as a consequence of the fact that Peter was infected with hepatitis C.

Section 7. Financial Assistance

37. I understand that Peter found out that there was financial assistance available to him by his liver consultant at St. James' Hospital in Leeds. I do not know when this was exactly but I assume it was a short time before the first payment was made in 2005.

38. Peter received a payment of £20,000 from the Skipton Fund on 6 January 2005. He received another payment on 27 June 2005 and I am unsure of the total amount received. I chased the Skipton Fund to find out how much this was, they were not able to confirm what it was but we think it was £25,000. There was another payment of £25,000 made to Peter's Estate on 15 February 2018. I was advised that this was to make up a shortfall in the payments that should have been received in 2011.

39. As far as I am aware, the process of applying for financial assistance was straight forward for Peter. He was supported by his medical team at St. James' Hospital in Leeds through the application process.

40. I understand that Peter did not experience difficulties or obstacles in applying for or obtaining financial assistance.

41. I am not aware of there being any preconditions imposed on the making of an application for, or grant of, financial assistance.

42. I have no other observations to make about the Funds.

43. I received a £10,000 bereavement payment on 20 January 2018. The total funds of £35,000 (£10,000 bereavement and £25,000 top up) that I received were distributed according to the wishes of Peter's Will. I also receive an annual winter fuel payment of around £519 from EIBSS which started in 2017. I did apply for a refund of funeral costs which was turned down.

Section 8. Other Issues

44. There are no other issues relevant to the Inquiry's Terms of Reference, which I wish to raise at this point in time.

45. There are no other documents that I wish to make available to the Inquiry that are in my possession and would be relevant to the Inquiry's Terms of Reference. As I have indicated above, the information included in the War Pension Claim information can be provided to the Inquiry teams should it determine that it would be helpful for me to do so; however, the content of the same has been shared within the body of this statement.

46. Peter and I had our wedding booked for 28 July 2008, which was only a couple of weeks after Peter passed away on 30 June 2008. As we were not actually married at the time of Peter's passing I was unable to receive his RAF pension which he had written and requested should be passed onto me.

47. Due to Peter's condition we could not afford to get insurance to cover the mortgage due to the high premiums because of his hepatitis c diagnosis. I am still 10 years following Peter's death paying the mortgage on our home.

48. I would like the Inquiry to have it recognised that hepatitis C drastically reduces life expectancy and creates financial hardship.

Statement of Truth

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

Signed: GRO-C

Full Name: Wendy Jean CAMPBELL

Date: 16 April 2019