

Witness Name: Brenda Hamilton

Statement No.: WITN4938001

Exhibits: WITN4938002 -3 (2)

Dated: 3 June 2021

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF BRENDA HAMILTON**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10 May 2021.

I, Brenda Hamilton, will say as follows: -

#### **Section 1. Introduction**

1. My name is Brenda Hamilton. My date of birth is GRO-C 1944 and my address is GRO-C Kent GRO-C I am retired, but worked as a Civil Servant in the Department of Transport for 20 years. I have two grown up children and four grandchildren.
  
2. I intend to make this statement about my late husband Thomas Hamilton, who was born on GRO-C 1943 and sadly passed away on 20 December 2016, at the age of 73. I will refer to him as Tommy, which is what I always called him. He was infected with Hepatitis C (HCV), as a result of receiving a blood transfusion after an appendectomy in 1985.

3. In particular, I intend to discuss the nature of his illness, how the illness affected him, the treatment received and the impact it had on him, me and our lives together.
4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.
5. I should point out that my recollections are quite hazy and can easily merge. I have relied upon some detail from my son Paul who had a lot of dealings with his father's health issues and following up things like his Skipton Fund applications. As I will go on to state, I have had mental health problems both with regard to Tommy's condition and care but also some pre-existing historical issues of my own.

## **Section 2. How Infected**

6. Tommy and I were married in 1966 at St Mary's Church, Lambeth Palace Road. We were together for 57 years and both led a clean, normal life. My husband never used intravenous drugs, never received any medical treatment abroad, and therefore he can only have contracted HCV due to the Health Service and through no fault of his own.
7. The first possible instance where my husband could have contracted HCV, though I do not personally believe this to have been when it happened, was in 1968, during surgery to remove varicose veins. The operation seemed to go well and he recovered satisfactorily. However, 20 years later, Tommy started to experience severe pain in both hips. He underwent a hip operation, but this did not stop the pain. The doctor then requested an x-ray and they noticed clips had been left in his groin since the varicose vein operation, 20 years earlier. Our son, Paul ended up driving Tommy to Wales, to see Tudor Davies, the surgeon who performed the operation in 1968. He explained that the clips would not cause any problem and as a result they were never removed. I am just providing this information to be complete, I am not saying or implying that this was the cause of Tommy's HCV.
8. My husband had no health issues between 1968 – 1985 other than type 2 diabetes. Our daughter was born in [GRO-C] 1968 and our son in [GRO-C] 1972.

9. Tommy had a second operation in 1985 – he was rushed into hospital with severe appendicitis and underwent an appendectomy. We were not aware that he received a blood transfusion until he was many years later diagnosed with HCV and we read through the medical records, where the likelihood at least, of Tommy needing a blood transfusion was written in black & white in a letter dated 3 February 2010 from Dr Deborah Enting in the Oncology Dept at Guy's & St Thomas. There is an arrow drawn and a line under the relevant passage. I do not know who did this. I exhibit this as WITN4938002.
10. Tommy did have a couple of bad bouts of cellulitis after the operation, again I am not saying that this was relevant to infected blood that he received.
11. My husband was a very hard worker – he was a drayman for Carlsberg and later became a postman for the General Post Office (GPO). His round covered Buckingham Palace and the Houses of Parliament. He was very active outside of work and played football until his mid-40s, which looking back I can say with some certainty that he stopped because of his ill health.
12. Tommy was medically retired from the GPO in 1996 – he felt tired all of the time and could no longer cope with his job. Looking back, his health was on a decline.
13. He was a very private and proud man and I think he did not let on how ill he felt. I remember how I could often hear him crying in the bathroom. I also noticed blood in his underpants when I did the washing but I made out that I was unaware. We were of a generation and background whereby as a couple but generally also, we just did not talk too much about medical issues and I did not want to pry or make him feel awkward. Looking back, this probably wasn't the best way to handle things but it was the way we were and generally the way it was back then.
14. In 1996 Tommy went on holiday with our son Paul to Tenerife. Paul recalls that his dad started to experience pain in his side, where his liver was. Though that is looking back and was not identified at the time. This may have been the first outward signs i.e. outside of what was being kept individually to ourselves within our marriage, of the problems he was having.

15. My husband and I lived in [GRO-C] for a further 7 years after his retirement, but after our son moved to [GRO-C] in 2000, we decided to follow and moved there in 2003. After the move, Tommy's health deteriorated and he lost a lot of weight. He was always asleep and his mood changed – he became very short-tempered and I believe at this point he knew something was wrong with his health. He started drinking heavily at the weekend which was very out of character. One night he came home drunk, fell onto the table, threw the chair across the room, and started sobbing his eyes out.
16. During this time, Tommy had frequent blood tests at Maidstone Hospital. He told me it was because of his diabetes, which I accepted. As I have alluded to above, I believe my husband knew a lot more about his health than he ever told me because I am a worrier.
17. In 2005 my husband received a letter instructing him to meet with Professor Black at Maidstone Hospital. I decided to accompany Tommy to the appointment because he had lost a lot of coordination by this time. The appointment ended up being on our wedding anniversary, [GRO-C] and we were told he had a tumour on his liver 3.5cm in size. He explained that Tommy would be assigned a nurse and put onto the liver transplant list immediately. He was told to stop drinking. The consultant said that Tommy would not stand a chance if the tumour grew another 2cm.
18. I nearly passed out when we came out of the appointment, but Tommy kept telling me not to worry. His attitude was very much to live for the day.
19. Two weeks after we were told about the tumour, an oncology nurse sat us down and told Tommy that he had hepatitis C. Tommy had no idea he was being tested for HCV and just presumed he was having blood tests for monitoring purposes. This is not to say that had he been told, then he would not have consented to the test, he would have.
20. We were provided with absolutely no information about HCV at all. We did not know how it would affect Tommy's health or how to prevent transmission of the

virus and manage infection. There was a severe lack of information and support and we were not even given any information booklets.

21. My son recalls one of the doctors commenting that by looking at Tommy's viral load, he could tell that his father had been infected for 15-20 years. This would put it fair and square around the time of Tommy's appendectomy in 1985.

### **Section 3. Other Infections**

22. Tommy did not contract any other infections other than HCV as a result of being given infected blood.

### **Section 4. Consent**

23. As far as I am aware, Tommy never specifically consented to be tested for HCV but did consent for his blood to be tested generally as part of his monitoring.

### **Section 5. Impact**

24. My husband was a very strong-minded man, but his infection with HCV did affect and change his character completely and he was not the same person.
25. Tommy waited 12-14 months on the liver transplant list. He lost a lot of weight during this time and became visibly very old. He would sleep all day and never had the energy to do anything. This we realised, was a continuation of his decline in health that led to his retirement and further deterioration before his cancer diagnosis. It makes absolute sense that his liver had been attacked by the HCV over a prolonged period of time going back to his appendectomy.
26. The liver transplant went ahead in 2006. The first call was not a match, but on the second he was blue lighted from Maidstone to Kings College Hospital. The operation was successful. He was kept in hospital for 3 weeks post-transplant and when he eventually came home I was shown how to change his bag, into which

fluids drained from his body in the area of his liver. I looked after him the best that I could, without being given any direction or training really.

27. Post-transplant, Tommy underwent a course of chemotherapy. I had to administer drugs via a picc line, which is a tube in the arm through which needles are inserted in cases where numerous injections are required to save breaking the skin each time. I was only given the quickest and most basic instruction and then just told to get on with it. He attended Kings for regular check-ups and during one of these appointments, Dr Heaton told us the cancer had spread to the rest of his body.
28. Treatment for HCV was never mentioned when Tommy was first diagnosed with the virus and he had to wait some years before it was offered. He had a course of Ribavirin, Interferon, and another drug – I distinctly remember there being three boxes of separate medication. We were told the course of treatment cost the NHS £38,000, which made me paranoid about getting crucial doses or timings wrong. I had to inject the Interferon into Tommy's stomach, but I was never given a proper demonstration, maybe one go with an orange and a syringe. The ribavirin was taken daily in tablet form. In the December we were told by Professor Heaton that the treatment had not been successful, but to have a lovely Christmas. Professor Heaton was not rude but very matter of fact in his bedside manner, I would not criticise him though, I wouldn't criticise any NHS worker. Tommy was devastated – he banged his head on the wall and went downhill quickly from this point.
29. A second treatment was offered in 2014 as part of a drug trial. Tommy said he would give anything to live, so agreed to participate in the clinical trial and attended a medical examination at Harley Street. It is very difficult to remember the different rounds of treatment individually, but I believe it was during the second that Tommy was tested twice a week at Kings. We thought the new medication would save him, but it had the opposite effect. I think I recall this medication being pegylated interferon. His hair fell out and his skin came off – it looked as though he had been burnt because his open flesh was exposed. The trial was stopped because of the effect on his skin. Sadly, Tommy never cleared the virus.
30. The Inquiry investigator has explained the term 'brain fog' to me as being a symptom of HCV. I was not aware of this, but it would accurately describe what

Tommy experienced. Tommy's short and long term memory was severely affected as a result of the HCV and in 2015 we thought he had early-onset dementia. No one ever explained to us using the term 'brain fog' or otherwise that it was a direct symptom of HCV. Paul stopped Tommy from driving in the end because he did not know what he was doing.

31. All of my husband's ailments conspired against his health and in the run-up to his death in 2016 he had two stays in hospital. The first was for a week, which we were told was due to sepsis. Tommy went to stay with Paul and his wife afterwards, but the decline in his health was very rapid and he was readmitted to hospital shortly after.
32. During his second bout in hospital and a week before he passed away, Tommy was diagnosed with lymphoma. We were told it was a result of the HCV infection attacking his liver, giving him cancer and that although the cancerous liver had been removed, this lymphoma was a secondary cancer. I distinctly remember one of the doctors saying rather bluntly how Tommy was so fortunate to live so long after his liver transplant. He explained that the average life expectancy post-transplant is 7 years. I do not know this doctors name but as I stated I would not criticise any of them.
33. Tommy refused to eat whilst in hospital, so Paul questioned one of the nurses about this. She explained that a loss of appetite is usually a sign that someone may be in the last days of their life. Two days before he died the lymphoma went to his brain and Tommy went blind.
34. On the day Tommy passed away (3 weeks after being readmitted to hospital) my children and I stayed by his bedside all day. When it got late, the nurse told us to go but as soon as we arrived home, I received a phone call to say he had passed away peacefully in his sleep. We went straight back to the hospital. I felt so numb after Tommy died and it did not fully register with me at first. 5 years later I still have moments when I expect him to be in the next room. I am still having therapy to help me grieve.

35. Lymphoma is the cause of death listed on my husband's death certificate. I am angry that there is no mention of HCV. The lymphoma was a knock-on effect of contracting HCV through no fault of his own. I exhibit Tommy's Death Certificate as WITN4938003.
36. Tommy required a lot of care post-transplant and I was on my own at home with him – as the children were busy with their own families and work commitments. The HCV medication also added additional pressure because I was told the medication had to be taken at the same time every day otherwise it would not work. Medical professionals from Kings would phone daily and make changes to Tommy's medication programme. During the drug trial, the twice weekly visits to Kings took its toll and we would have to wait hours after the appointment to be taken home by an ambulance that did a 'round robin' picking up and dropping off other patients.
37. I have always suffered with my mental health due to events that have happened in the past, not relevant here. I have always been someone's unpaid carer, dealing with their problems and this has ultimately taken its toll on me. It took a long time before I flipped because I kept everything to myself and I did not let on to anyone that I could not cope, again that traditional generational thing and it built up within me until I could not keep it back any more. I bottled everything up over the years and put on an act that I was coping well, but in reality, I often went to bed crying and would wake up in the night to check if Tommy was still breathing. I had to wake up early to prepare his medication for the day, but one morning I snapped and smashed up everything in the kitchen.
38. My GP referred me to see a psychiatrist because I said how I could not cope with all of Tommy's medication, the change in character and our relationship also. I had 2 breakdowns and spent time in a psychiatric ward. At times I have been sectioned. I was in hospital during Tommy's first stay in hospital but discharged myself when he was sent home.
39. I kept quiet about my illness because I thought it was embarrassing that I could not cope with looking after my husband, whom I married "in sickness and in



health". I still feel guilty that I have always helped others, but could not cope with my own husband's ill health. This pulls me down a lot and to this day, I feel as though I should have done more for him.

40. I am still very affected by everything and am still on medication for my mental health. I have been diagnosed with having Post Traumatic Stress Disorder and have regular visits from Community Psychiatric Nurses. As a result of COVID-19, I attend zoom calls 3 times a week.
41. I felt and still feel such a sense of guilt about how I felt about Tommy's HCV infection. I am ashamed to say that I could not bear to touch him because I was scared of contracting the virus and I even bought a cap to put over my toothbrush, so he did not mistakenly use it. I did not even like picking up his washing, because I was paranoid about contracting HCV and then passing it on to others, maybe even my grandchildren. All because no medical professional ever provided information on how it was transmitted and could be managed. I did not know anything and was living in the fear of the unknown. Perhaps I would have been more frightened if I knew the full information, but I should have been fully informed.
42. Tommy experienced blackouts toward the end of his life and on one occasion he fell. There was blood everywhere, but I was petrified to help in case I caught the virus. I felt so guilty that I did not help him.
43. I did not tell the children how I felt about their Dad and we never spoke about the HCV infection as a family – we knew nothing about the virus and I thought it was something drug addicts cause from sharing needles.
44. I do not know how my children felt about their mother being in and out of a psychiatric ward and I have never asked them. I know they have both suffered as a result of their father's HCV infection and my health issues. When they used to come in to visit me I used to worry about what they thought of me.
45. Many years after Tommy was diagnosed with HCV, my GP recommended that I should also be tested. She still did not provide any information on how I could contract the virus. Thankfully, I was negative but there were years and years of

him having HCV without even anyone knowing about it, including him, let alone being careful not to infect others.

46. As far as I am aware, my husband never received any difference in medical treatment because of his HCV infection. He never used to go to the dentist.

#### **Section 6. Treatment/Care/Support**

47. Tommy and I were never offered any counselling or psychological support as a result of his HCV infection. Obviously, indirectly I have had such support but not as a result of someone recognising that a lot of my issues related to Tommy's condition until it all came out in sessions.

#### **Section 7. Financial Assistance**

48. The oncology nurse informed us about the Skipton Fund and explained it was set up by the government to help those who had contracted HCV from infected blood. I am a pessimistic person and said to my husband not to bother applying, but he replied 'why shouldn't I, I am the one suffering as a result of this'. Paul assisted Tommy with the application forms and the first application was made in 2005.
49. We had to fight to get my husband's medical records from St Thomas', which we eventually received. The most relevant documents were sent as supporting exhibits for the Skipton application, including the mention of haemostasis and a letter from Dr Heaton stating that Tommy would have more than likely received blood when he had the appendectomy in 1985.
50. The initial application was rejected – I do not recall the reason why, only that we had the option to appeal. Paul was very determined to reapply because Tommy was still on the medication and he was entitled to the money. An appeal was made in 2009, I believe.

51. After the appeal was rejected I told my husband not to worry about the Skipton Fund, but he said he was doing it "for you and our children to make sure you are looked after when I'm gone" – those words have stuck with me since.
52. I now shudder when the Skipton Fund is mentioned – it was a complete locked door and they rubbished everything. I cannot understand how strangers can decide whether someone receives financial assistance when they do not know the individual.

### **Section 8. Other Issues**

53. My experience so far with the contaminated blood scandal is that nothing has ever materialised and we have never received any form of closure. The only reason I am here today and providing a statement to the Inquiry is because my son does not want his father to die in vain.

### **Statement of Truth**

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

Signed \_\_\_\_\_ GRO-C

Dated 03.06.21