Witness Name: Clive Standing
Statement No.: WITN5585001
Exhibits; WITN5585002-9
Dated; 8/3/21

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CLIVE STANDING

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 21 January 2021.

I, Clive Standing, will say as follows: -

Section 1. Introduction

1. My name is Clive Standing and I live at an address known to the Inquiry. My date of birth is GRO-C 1946. I am retired now but used to work as a railway signaller and now live alone. I have three children and two granddaughters.

2. I intend to speak about my late wife, Jacqueline Joan Standing who was born on GRO-C 1953. I met Jacqueline's twin sister in the early 1970s, at GRO-C Cricket Club, where I played for the railway's cricket team. I was introduced to Jackie a short while after and we were married in 1972.

3. In particular, I will discuss how she came to be infected with hepatitis C (HCV), the nature of her illness, the treatment she subsequently

received, the experience of applying for financial assistance and the impact it had on her and our family. Her death certificate is shown here (**Exhibit WITN5585002**).

4. I can confirm that I am not legally represented and that the provisions of the anonymity policy have been explained to me and I am happy for my story and that of my wife to be in the public domain.

Section 2. How Infected

5. Jackie and I had our eldest daughter in 1972, the year we got married. There were no complications and it was a normal birth. Several years later, in 1975, whilst pregnant with our second child Jackie complained of having severe abdominal pain during the night and was bleeding from her vagina – so much blood that she was wearing a towel to catch it all. An on-call doctor came out to see her several times over the course of the week – each time, the doctor just told us she was pregnant and it was related. She was still bleeding very heavily. He estimated that she was further and further along in her pregnancy each time. It was as though she went from being a matter of weeks, then a month, then several months into the pregnancy over the course of a few days. The bleeding did not stop.

6. The final time this doctor came (I think it was his fifth visit), I demanded that Jackie be taken to the hospital – something was clearly not right. She was taken to All Saints Hospital, Chatham – it is no longer there. I couldn't go with her as I need to look after our young daughter. I rang the hospital first thing in the morning and was told that Jackie was in theatre. When I was allowed to visit her, I arranged care for our daughter and went into the hospital.

7. When I arrived, a sister on the ward told me that the child had been growing outside of the womb and Jackie had miscarried. She called it an ectopic pregnancy. When I saw my wife, she was in bed, with the curtains pulled around her cubicle, hooked up to a number of bottles

filled with blood. I remember it very distinctly as I very rarely faint, but for some reason, when they came to change the blood, seeing all this blood going into her caused me to briefly pass out. I remember they were round clear bottles, though I am not sure if they were made of plastic or glass. I recall that they said they would need to change it again at some stage and my wife made me leave when they did so I did not pass out again.

8. According to a letter from the gynaecological surgeon, Dr S Aziz, dated 4 June 1975 (**Exhibit WITN5585003**), they had discovered my wife had a "*full molar pregnancy*" and a hysterotomy was carried out on GRO-C 1975. This is confirmed in a letter to Dr Karim, our GP at the time which shows that Jackie was to be discharged on GRO-C '75. She was kept in hospital for two weeks. **(Exhibit WITN5585004)** Until recently I had always thought it was a hysterectomy and wondered how we had gone on to have further children but now it makes sense. I will comment on this diagnosis later in my statement. At the time, we were advised not to try for another child for at least nine months.

9. On 02 July 1975 there was a further letter from Dr Aziz. After a follow up visit, he mentions that Jackie is still bleeding and that if it continues they may need to consider a diagnostic curettage. **(Exhibit WITN5165005).** Later that month she underwent such an operation **(Exhibit WITN5585006)** which surely indicates that her bleeding problems were ongoing and more than minor.

10. As far as I am aware, this is the only instance of Jackie receiving a blood transfusion, except one in 2000 at the William Harvey Hospital, though, as far as I understand it, this is after full HCV testing of all blood donations was implemented. She never used drugs of any kind and we were faithful to one another from the day we got together. She had one small tattoo, but this was done at a professional, fully licensed vendor in GRO-C

11. We went on to have two more healthy children – I do not believe that my wife needed any further transfusions or treatment with blood products during these births.

12. Jackie as the years passed was frequently in and out of hospital. She had lots of issues with her health in general – she developed arthritis in all her joints, had persistent problems with her sight, asthma, anaemia, diabetes in later life and so on. She also had mental health issues. I know little about it, but I believe that GRO-D during her childhood and she suffered from PTSD and depression at various points throughout her life.

13. In the early 1990s, Jackie was sectioned in Medway Hospital and was then taken to Ticehurst House Hospital, a mental health facility in Sussex. After being barred from seeing her for three months, I was gradually allowed to visit her more frequently until she was eventually allowed home. She continued to struggle with her mental health for the remainder of her life and was on various medications for these problems.

14. By the late 1990s, Jackie was almost completely blind and continuing to struggle with all manner of health conditions. We were registered at New Romney Surgery, where our GP would see my wife regularly, but were also being frequently directed to William Harvey Hospital for Jackie's more specialist treatments. She was tested for all sorts of things all the time, such was the nature of her complex health requirements. There were a lot of delays caused by the constant referrals and it would take a long time to see anyone to get to the bottom of whichever problem they were looking at. I almost always accompanied her and we spent so much time in hospital, basically more than we spent anywhere else.

15. In January 2014, I took Jackie in for a routine appointment at the William Harvey Hospital and we were informed that Jackie had tested positive for HCV. I often wonder why it took so long for this diagnosis to surface considering the number of blood tests that my wife underwent during the intervening years. We were then referred to Kings College Hospital in

London to see a liver specialist. They asked us both lots of questions about my wife's personal history – drug use, promiscuity and so on. The only possible route of infection I could offer them was the blood transfusions I recalled her having back in 1975. I believe she may also have been tested for HIV at this point too. Though I do not have documents directly from the HCV diagnosis itself, I do have another letter that refers to it. (**Exhibit WITN5585007**).

Section 3. Other Infections

16. As far as I am aware, there is no suggestion that Jackie was exposed to any infection other than HCV as a result of her receiving blood transfusions. It is not possible for me to say whether the HCV caused or impacted on any of the many other medical conditions my wife suffered from in her later life but I am certain that it could not have helped.

Section 4. Consent

17. As far as I recollect, there was no information given to my wife or myself as to the risk of infection arising from the receipt of a blood transfusion, though I imagine that my wife would not have been in a fit state to understand such information or consent to the treatment and I was not there when it was administered.

18. Jackie was constantly being tested, for so many different things, that I do not think we would have given our specific consent for her to be tested for HCV. That said, I have no recollection of us being told that she was going to be tested for the virus and cannot say what prompted them to test her for HCV.

19. I do not think that my wife was given any treatment for her HCV infection without her specific consent or entered into a clinical trial without her knowledge. She was given an experimental drug for the infection, which I will detail further at Section 5, below, but I remember that we signed a document to agree to her being given this treatment.

Section 5. Treatment/Care/Support

20. After Jackie's HCV was diagnosed in 2014, we were regularly travelling to London to see a specialist in hepatitis infection, Dr Ivana Carey at Kings College. She gave us lots of information and was very good at explaining all the details to us. Jackie was put on an experimental drug called Harvoni, with Ribavirin also given as an inhibitor I believe.

21. Also, at Kings College, Jackie was sent for liver biopsies and scans, including ultrasound. Unfortunately, due to the number of procedures she was subjected to and the frequency I cannot recall the exact outcome of these although I believe she did have some liver damage.

22. The treatment consisted of tablets to be taken daily, dispensed at weekly intervals. We were told that the treatment may be able to clear the virus completely, but were warned that the damage to Jackie's organs was not yet fully known. Four or five months after the treatment began, we were told by the nurse at Kings College Hospital that the virus had been cleared by the medication. During that time, we travelled back and forward on a regular basis so that she could be tested and monitored as to how the treatment was progressing. When Jackie was given the all clear that monitoring was to continue for a while, but we were discharged back to William Harvey hospital. This was partly a result of our own request as it was awful travelling all the way to London so frequently and the arduous journey was beginning to have a negative impact on Jackie's health and mental well-being.

23. Neither Jackie or I were offered the option of psychological counselling. Not at the point of diagnosis nor later during treatment. She did receive support through MIND, the mental health charity with whom she was involved from her days in Ticehurst and she had undergone psychological treatment over the years for her depression.

Section 6. Impact

24. The initial HCV diagnosis hit Jackie very badly – she was in tears for weeks. She couldn't understand how she could have contracted it. It made her feel dirty. When we were initially told about it at William Harvey Hospital, we were given no information about what it meant for us. Nothing about precautions to take or what the diagnosis would mean for our future. We were both left completely devastated. Later on, we were reassured a lot more by the specialists at Kings and given information on the impact it may have and ways to prevent further infection and that sort of thing.

25. It was also as you would expect a worrying time whilst we waited for the children to be tested. Nothing was said about this at the initial diagnosis but Dr Carey at Kings suggested that they should undergo testing. Fortunately, they all came back clear but I dread to think how my wife felt during that time wondering if she had passed on a possible fatal infection to her children

26. As previously stated, Jackie had a huge number of health issues over the course of her life. It is, therefore, very difficult to isolate any possible symptom of her infection with HCV and attribute it to the virus. As mentioned earlier, there is no health issue that I can be certain was caused distinctively by her hepatitis infection, but I can only imagine that it exacerbated a lot of her other conditions. She would have these 'blank moments' where she completely lost her trail of thought and she did develop memory problems. It is also true to say she was very often exhausted, easily fatigued - more than was normal - and often felt uncomfortable within herself.

27. The most significant post-diagnosis impact was the stress of frequent trips to London. We were already constantly going between the GP's surgery and William Harvey Hospital, so it was just another strain on both of us. For a few months we travelled all the way to Kings at least once a week, often several times a week, for various assessments. They

would have us there for a blood test one day and then want us back the next day for a scan. At times these trips could take anything from 8-10 hours. They were physically and mentally draining for both of us but particularly for my wife bearing in mind the extent of her complications. After a lot of effort on my part, we managed to get them to at least try and consolidate these appointments into as few trips as possible.

28. Jackie hated every moment of it all. I had to fight with her to get her to appointments – she never wanted to go. I was very accustomed to travelling frequently for work, but it took a huge toll on her. Her mental health problems were always close to the surface, but they definitely came to the fore in this period. She would talk about self-harm and threaten to end her life. I knew how to deal with this though – it was just a matter of talking to her about it. But being prodded and poked for so long took a huge toll on her emotional and mental well-being.

29. As with the infection itself, it is difficult to distinguish between any possible side effects of Jackie's HCV treatment and the other health problems she suffered with. I don't think that there was anything particularly abnormal about the effects of the drug – it must be remembered that she was already blind and completely reliant on me for many things anyway, so it was quite hard to pinpoint any difficulties caused exclusively by the HCV treatment.

30. Though we got a lot of help from relatives, particularly Jackie's twin sister, I was also under a monumental strain. I was very used to caring for my wife for years before her HCV diagnosis, but it definitely added new element to the stress that I felt. I was signed off work with high blood pressure for a short time. I ended up taking early retirement shortly after this; caring for my wife was my primary concern and it became too difficult to juggle it alongside a career.

31. A short time before I retired, disciplinary proceedings were started against me because of a mistake that I made. Working with railway signalling means that you have to be very focussed and free from

distraction, so we weren't allowed mobile phones. I needed to ensure that I was available if my wife contacted me, so I would get in trouble for having my phone on me and that led to the proceedings. This brought into focus the difficulties of balancing work with her care.

32. I sorted out all the figures and worked out that we just be able to manage if I took an early retirement. I had a very good position and possibly could have gone higher and there was obviously going to be a big financial impact from this but with Jackie's health and my own to consider it was the only thing to do. It was a bit of a struggle but we managed. There was no impact on things such as mortgage or travel insurance as there was not much time between diagnosis and her passing.

33. The stigma associated with HCV did cause my wife to worry, but it was more that she herself hated the associations than us actually being stigmatised by others. The idea of being lumped in with drug users and the like was not at all nice for her. A couple of her friends knew about her HCV and Jackie worried that they didn't come to see her because of the infection, but there were lots of other reasons that I believe were actually behind it – we had moved away from a lot of them, for example.

34. In July 2015, I woke up to find Jackie unconscious. I was completely unable to wake her. I believed that she had gone into a diabetic coma, as did the paramedic that attended. She was taken to William Harvey Hospital, who had been in contact with Kings by the time we got there. Kings had advised the doctor's at William Harvey what should be done when she arrived, such as all the wires and monitors and so on.

35. She regained consciousness whilst at William Harvey, but they couldn't manage her there; she was very distressed and pulled all of the cannulas and tubes out. When I got there, I helped to calm her down and get them all back in so that she could be taken to Kings where they could treat her. The ambulance was not allowed to travel faster than 20mph due to her condition and I was told to travel separately so I arrived at Kings two

hours before the ambulance did, having driven to GRO-C and getting the train to London from there.

36. Jackie was put on to a specialised unit, with her own cubicle. Like everyone else on the ward, she was hooked up to all sorts of monitors, machinery and bags. I remember thinking that it looked like the deck of the Enterprise from Star Trek – all the beeps, buttons and flashing lights.

37. If I remember correctly, Jackie arrived there on the Sunday and, by the following weekend, we were told that nothing more could be done for her. The doctors on the unit were very good and kept me well informed of her condition, but I was told that the damage to her organs was so far advanced that there was nothing they could do to help her any more. I know the liver was definitely mentioned, though again I can't single out exactly what was said about it. Most of it was a blur and I had my mind only on what was happening to my wife.

38. The doctor told me that they could keep her alive with the help of about 60 different pieces of machinery and equipment, but that's all it would be – keeping her alive. I had discussed this situation with Jackie previously and we had agreed that I would let her go if this happened. I spoke to my daughters about it and they agreed that it was best to let her go. It took a little while longer for my son to fully accept it – he broke down on the day. The girls were stronger.

39. On 19 July 2015, I gave permission for the doctors to withdraw life support and my wife passed away. Her death certificate (**Exhibit WITN5585002**) states that the direct cause of death was multiple organ failure, but *"Decompensated Liver Disease"* and *"Hepatitis C Liver Cirrhosis"* are listed as the secondary causes. There were no issues in relation to her body after she passed away.

40. Whilst we were all completely devastated by the loss of Jackie, the youngest two suffered the most. I had spent many years caring for my wife and knew how bad her health was getting over the previous years.

Our eldest daughter was closer to me than she was to her mother. My younger daughter had worked in care homes and hospitals and so had been exposed to death, but it did have a tremendous effect on her. It was my son, however, that suffered the biggest impact from the loss of his mother. Both of the younger two withdrew for a period and it took them a long time to come to terms with the bereavement. I am not sure that my son ever fully has.

41. As for myself; even though I knew it would come someday and was fully aware of her medical problems I was still heartbroken. We had been together for such a long time. The anguish and guilt that comes with making the decision to 'pull the plug' is something that is hard to live with despite the knowledge it was by prior agreement.

Section 7. Financial Assistance

42. We were informed about the Skipton Fund by Dr Carey, at Kings College Hospital. I applied in July 2015, just before Jackie's death. I filled in the form on her behalf and sent it off. There weren't any particular difficulties with it. However, it was returned to me, saying that the doctor's section wasn't completed, so I got this filled in by Dr Carey and sent it off again.

43. I received a letter shortly afterwards saying that the Skipton Fund had rejected my application on the basis of a lack of evidence that a blood transfusion took place I have been made aware this was in January 2016. I had applied to all the relevant institutions to get Jackie's medical records, but they nearly all told me that the records will have been destroyed. East Kent Hospitals Trust replied that they had nothing before 1999. I did get some records from Maidstone Primary Care Trust and I provided everything that I had been able to get to the Fund, so there was not much more I could do.

44. The Skipton Fund also used a letter from one of the consultants at Kings following an appointment in November 2014 (**WITN5585008**) as a basis for rejecting my application. The letter does say, *"[w]ith regards to the*

hepatitis C she reports that she has not had any blood transfusions or previous intravenous drug use." This is simply an error. As far as I am able to recall the conversation that this is comment is based upon, we actually told the doctor that we could not remember the exact timescale for the transfusion, not that Jackie had never had one.

45. It was nothing more than a simple error in this letter, but the Fund used it to deny me financial assistance. I exhibit my reply to the rejection, which details my response to this point in full (**Exhibit WITN5585009**), dated 20 January 2016. I included this as part of the appeal process to have the original decision reviewed. However, this was also rejected and I am aware that this decision was sent to me in a letter dated 15 March 2016. Once again, the same conversation was quoted as the main reason together with the fact there was nothing in the medical notes I had submitted that suggested a transfusion took place.

46. To a degree I can understand why it was refused as it does not say in black and white in Jackie's notes that a transfusion took place but I saw it happen. I was quite upset as her death was still quite raw and here was what I believe to be a major contributory factor being dismissed as not having taken place.

Section 8. Other Issues

47. I would like to say that until I received these papers from Maidstone, for all my life I have believed that my wife suffered an ectopic pregnancy in 1975. That is what the sister on the ward called it. At no time did any doctor or other staff member explain it as anything else. I now saw in the notes that it was a 'molar pregnancy'. It would have been nice for someone to have taken the time to give a proper explanation. After all, we had just lost a child. I wonder how much this trauma contributed to my wife's later psychological problems.

48. GRO-C

GRO-C

GRO-C My granddaughter has already been deprived by the HCV of having her Gran in her life.

49. From what I know about the infected blood scandal, it certainly shouldn't have happened. I'm not medically trained, but I know that the testing regime wasn't as good as it should have been back then. That said, I am also a realist in many ways. Where were they supposed to get the blood from if there was a shortage? It has been the subsequent lack of support that has been the hardest to come to terms with

Statement of Truth

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

Signed GRO-C

Dated 8/3/21