Witness Name: Anthony Leone
Statement No.: WITN4765001
Exhibits: **WITN4765002 - 005**
Dated: 12-10-21

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ANTHONY LEONE

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

I, Anthony Leone, will say as follows: -

Section 1. Introduction

1. My name is Anthony Leone. My date of birth is GRO-C 1945, and my address is known to the Inquiry. I took early retirement, but I used to be a railway area relief worker. I live with my partner Margaret, and I have two children, and Margaret's got four. Margaret and I have been together since 2001. My wife died in 1992.

2. I intend to speak about my infection with hepatitis C ("HCV"). In particular, the nature of my illness, how the illness affected me, the treatment I have received and the impact it has had on my family and our lives together.

3. I am not legally represented and having had the provisions of the anonymity rules explained to me, I am happy for this statement to be in the public domain.

Section 2. How Infected

4. In June 1991, I was working on the railway when I had a heart-related episode. I thought it was a heart attack, and I went to Papworth Hospital (now known as the Royal Papworth Hospital). They informed me that I would need a triple bypass operation. The surgeon I saw was Mr Wallwork.

5. During the operation, the doctors woke me up to let me know that they had punctured one of my lungs and asked for permission to repair it. I can still recall that clearly. They must have been about halfway through the procedure, and I can actually remember the words to the effect of; "Mr Leone, we have accidentally punctured your lung, and we need your permission to correct it." Obviously, I agreed. What else could I do?

6. I stayed at the hospital for a week after the operation and was seen by another doctor. I think he was from Wales but was living in Norfolk at the time. I was taken for several X-rays, and I remember asking this doctor why I was still in the hospital, to which he responded, "it's because you are in a bad way".

7. The operation was a success, and I was later discharged from the hospital.

8. I believe that this was when I was given a blood transfusion. I don't specifically recall the transfusion and there is nothing in my medical records. My wife and her brother were with me at the hospital, but both of them have now passed away.

9. I have never had a blood transfusion on any other occasion. The only time I would have had one is during that operation. I have never been an intravenous drug user, I have no tattoos or piercings, and I have never had any medical treatment abroad and I was happily married to my wife.

10. In December 1995, I was contacted by Addenbrookes hospital by telephone. They asked if it would be okay for someone to come over to my house to take a blood sample from me and I said that this was fine. When the doctor arrived, she came with a list of names and informed me that there was a possibility that I had received infected blood and could be infected with HCV. I was stunned. I didn't really understand what HCV was. The doctor did not provide any further information just that I would hear back from them.

11. My wife had passed away a few years before, and I was seeing a woman, Bev, who was in medical personnel at the time. My partner gave me a number for someone I could contact directly at Addenbrooke's hospital's haematology department. I was worried by what had gone on and I didn't want to wait too long so I called the hospital.

12. The person I spoke to confirmed that I had been infected with HCV. I don't remember too much more of the conversation as I was a bit upset but I do recall being told that the blood may have come from a drug addict in Cambridge. That stuck in my mind as I wondered how they would know.

13. A couple of weeks later, I received a call from Addenbrookes hospital informing me to visit my GP Surgery. My doctor, Dr Lockett at GRO-C confirmed that I was HCV positive. I exhibit **WITN4765002**, the blood test result collected on 7 December 1995, which confirms my HCV positive diagnosis.

14. Dr Lockett informed me that I would need regular blood tests and referred me to a Gastroenterologist, Dr Kennedy, at another West Norwich Hospital, which is now a walk-in centre, for further tests.

15. I am not sure I had a proper understanding of the infection, what it meant for me going forward. My partner, Bev, was my main source of information because the doctors did not provide much.

16. They told me to look in the mirror every day, pull down my eyelids to check for symptoms like jaundice. They also said I should not share a toothbrush with someone else and not to have unprotected sex.

17. Subsequently, I had at least three appointments with Dr Kennedy and my GP and blood tests on those occasions confirming I had HCV. I exhibit **WITN4765003**, which confirms that I was HCV positive at my appointment with Dr Kennedy on 15 May 1996.

18. In 1997, I visited doctor Kennedy again, and he took a blood sample and later confirmed that I was HCV positive. However, in 1998, after another visit to Dr Kennedy in which another blood test had been completed, my doctor informed me that the blood test results were negative for HCV, which meant that I had cleared the infection naturally. I exhibit as **WITN4765004,** microbiology and serology results following both visits to Dr Kennedy, which shows I was HCV positive from the blood tests done on 6 January 1997, and negative PCR on 17 February 1998.

Section 3. Other Infections

19. I do not believe that I have received any infection or infections other than HCV due to being given infected blood, although I don't know if I have ever been tested for HIV. Nothing to that effect was ever mentioned.

Section 4. Consent

20. I do not believe that I have been treated or tested without their knowledge or consent. I was informed that my blood would be tested for HCV when the doctor came around to my house. However, I was never asked for consent at the time I believe that I had my blood transfusion and I was never provided with information about any potential risks associated with such a procedure.

Section 5. Impact

21. When I came out of the hospital after the heart transplant, I was not in the best frame of mind. I had been informed that I would have to go back in to see Dr Wallwork in a month, and my wife was diagnosed with breast cancer. It was a traumatic time for myself and my family.

22. During the year after my wife's diagnosis, I had no time to really think, and I would not have noticed if I was experiencing symptoms of any kind I was too pre-occupied with providing care and comfort for my wife and family to think of myself.

23. We thought that she had it cleared, then her cancer came back, and my wife passed away in 1992. I was under a lot of stress at the time and full of grief at her passing. I found it hard to face every-day matters work gave me six months off to grieve and recover.

24. After my wife passed away, my family situation got even more stressful as one of my son's GRO-C due to his mother's passing and the manner in which it happened. It was difficult to cope.

25. I had only been with Bev for a little while when I was diagnosed with HCV, and we were together for around five or six years. I relied on Bev for information and support during that period. She used to work for BUPA, so I assume that she also got tested after I was diagnosed with

HCV and that her results were negative. No one amongst the medical professionals ever suggested she should get tested nor any other members of my family.

26. After I found out that I was HCV positive, I was very upset. I had gone in for a procedure for my heart, they had traumatised me by waking me up in the middle of surgery to let me know they had punctured my lung, and worse, they had given me an infection that could potentially endanger my life.

27. However, I had to continue to carry on as normal, so I pushed it to the back of my mind. Nobody told me not to drink alcohol, so I could still go out and socialise with friends and I used this to unwind.

28. I had to have an ultrasound, but I don't think I had a liver biopsy. I don't recall anyone telling me about whether I had suffered from liver damage at the time, and they did not refer me for any treatment.

29. Around 1997 or 1998, an opportunity arose at work to have early retirement. It had nothing to do with my health, and I was only 52 years at the time, but it suited me fine.

30. I didn't notice any HCV symptoms back then, but now I do. I suffer from fatigue and night sweats, the latter of which I think began about four years ago. It gets so bad that I often have to change t-shirts in the middle of the night. I get very easily tired after any kind of exertion. Margaret says I have raised moles on my back, and she thinks I have had them since back then. I also suffer from memory issues and sometimes forget the thread of a conversation. I don't believe that any of this is age-related. The doctors have said that they are getting me an appointment for that.

31. Margaret also says that I have a strange condition that has been going on for at least 12 or 15 years now, where I sort of pass out at random moments. For example, I could be in the middle of drinking water and

pass out with the drink still to my mouth in mid flow. She would have to grab the glass from my hand. Margaret says that I may go a year without having one of these episodes, but sometimes I could have it happen 2 or 3 times in the space of a few months.

32. I have had a triple laminectomy on my back and a hip operation, both of which are probably age-related, and I also experience shakes.

33. Although I met Margaret after being informed I cleared the infection, I was still under the impression that I had HCV. I must have thought it was still there or lying dormant, but Margaret recalls me informing her when we met that I had HCV.

34. As a result, for a long time, Margaret was worried about catching it. Even realising that I had cleared it, we thought it was still there and dormant and could come surface again. I was extremely anxious for a long time that it would resurface, and I would pass it on to Margaret.

35. I don't think I have suffered from any negative treatment at the hands of other medical professionals. I can recall mentioning it to my dentists when I went in for a procedure, but they did not treat me any differently.

36. There was no stigma related problems as I kept it pretty much to myself and within the family

Section 6. Treatment/Care/Support

37. Before I was informed I had cleared the HCV naturally, I was not offered any treatment. I am not sure why, but they may not have thought I was a priority. I did have the infection when being tested for at least a full year, possibly two, before showing as clear, as the results prove. But that is only the period they know about. How long was it in my system prior to that and what damage did it do? I am left with the residual effects

of that now. They did not even inform me about the state of my liver and I wonder what the impact has been on it although I am told it is fine.

38. I was not offered any counselling or psychological support at any point, not for myself or my family.

Section 7. Financial Assistance

39. I was listening to the radio, I think it was Tony Blair, the Prime Minister at the time, speaking about the infected blood scandal. He mentioned the Skipton Fund as one of the organisations set up to provide financial support to people who had been affected, and I decided to apply for support.

40. I am not sure how I obtained the form, but I know that Dr Lockett assisted me in completing the form.

41. In March 2009, the Fund refused my application. I thought it was unfair and I was disappointed by their reaction so I appealed to the Skipton Appeals Panel in May 2009.

42. I explained to the Panel that through no fault of my own, I was given infected blood. In my letter to the Panel, I also explained what I had been told about clearing the infection. "They said if the virus clears itself after six months, it is a rarity. The blood sample was taken four and half years after infection and was still there". My own test results show I was positive for over a year at least. I exhibit as **WITN4765005** the letter I wrote to the Skipton panel dated 24 May 2009

43. On 27 July 2009, the Panel rejected my appeal on the basis that I had a negative PCR test. They suggested that I had cleared the virus in far less than six months. I was completely dismayed and felt let down by the Fund and the system.

44. In the refusal, the Panel stated that "The Panel reviewed the entire file of papers held by the Skipton fund in connection with your appeal and the additional information supplied for the purpose of the appeal. The expert advice we have received is that the overwhelming majority of those who are infected but later have negative PCR blood tests clear the virus is far less than six months. We noticed that there was no evidence on your file that your infection with Hep C lasted more than six months or more contrary to the experience of the majority."

45. As far as I am concerned, I had the infection in my blood from the time my diagnosis was confirmed in 1995 until the doctor told me I had cleared it in 1998. During that time, I have tested HCV positive following a blood sample I gave to Addenbrooke's Hospital in 1995, I saw a doctor in May 1996. That test also came out positive, and in 1997 on a visit to Dr Kennedy, I also had an HCV positive test.

46. I still have a blood test annually, to monitor my liver function, among other things, and they make a point of saying that my liver function is fine. About two weeks ago, I had one again, but I have not yet heard the results this time.

47. I was informed that in 2005, I had a further blood test for HCV at my GP's surgery, which was again shown to be negative, but I cannot remember that specific test and the result.

Section 8. Other Issues

48. In 2013, I was asked to take part in a trial conducted by the Hepatology Research Group. I think it was because I had cleared HCV naturally, and they wanted to analyse my blood regarding this. A Dr Maggie Ow from Derriford hospital in Plymouth attended my home and took my blood for tests. I never heard anything back from the group after that.

took my blood for tests GRO-C. I never heard anything back GRO-C from the group after that.

49. I was informed that when I was infected, i.e. during my heart operation, there wasn't a test available to check the blood. However, my partner at the time, Bev, said that this was not true as there was, and the French and Americans were using the test, but evidently, we did not.

50. When I found this out, I was disappointed that I had not been tested much earlier. If the blood wasn't screened at the time surely, I could have been called in earlier than four years later as they must have had an idea that the blood used was potentially infected. When I was told that I had cleared the HCV, I was relieved, but it did not put my mind to rest.

51. I have been reminded that I considered suing the NHS, but my solicitors in 1996 told me that it was a waste of time trying and I should wait to find groups of people who had suffered the same, Unfortunately, I can't remember much about seeing the solicitor.

52. I went into the hospital to be cured of one complaint, but because my lung got punctured, through no fault of my own, I came out with a potential death sentence hanging over my head – which to my mind has not necessarily gone away.

Statement of Truth

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

Signed GRO-C

Dated 12th October - 2021