Witness Name: Robert Norman Bamforth
Statement No: WITN4414001
Exhibits: **WITN4414002 - 013**
Dated: 09 October 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ROBERT NORMAN BAMFORTH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 26 June 2020.

I, Robert Norman Bamforth, will say as follows: -

Section 1. Introduction

1. My name is Robert Norman Bamforth. My date of birth is GRO-C 1947 and my address is GRO-C. I have recently stopped working as a barber due to Covid-19, a profession I have been involved in for over 20 years. Prior to that I worked as an aircraft engineer and production manager.

2. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I am not seeking anonymity as I wish for my story to be known in full.

3. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

4. I have been married three times, and I now live with my partner. I am the father to two sons and two step-children, I am also a proud grandfather.

5. 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 received and the impact it had on me, my family and our lives together.

Section 2. How Infected

6. When I left school, I couldn't read or write because of my severe dyslexia, which still affects me to this day. I decided to train as a hairdresser. At the college during my training I began to realise that I could do much more than I thought, despite my difficulties at school.

7. I used this experience to train as an aircraft engineer. I began to work my way up, eventually gaining a senior role as a production manager. I was involved in the restoration and refurbishment of classic aircraft, including spitfires and hurricanes from the Second World War.

8. I married my first wife in 1967. This marriage lasted for 11 years until we separated around 1978. I then lived alone for around 9 years, during which time I had one girlfriend. I met my second wife in 1986.

9. I had an accident around 1986, when I was aged 39, I broke my ankle badly. I was skateboarding at a skatepark with my sons when I put my foot down to stop. This caused my ankle to snap and I flew up in the air. When I landed and looked down I saw my ankle almost hanging off.

It was only being held together by the skin. An ambulance was called and I was rushed to the Lister Hospital in Stevenage.

10. At the Lister Hospital I was taken straight into A&E, sometime later that day I underwent an operation to repair the damage. They bolted my ankle back on, and when I woke up my leg was in the air in a plaster.

11. From memory my ankle had started to swell and within the day they had to cut the cast to allow for expansion. Not long after this my ankle started to smell really badly, it stank. I then remember the consultant coming round and telling them to take the plaster completely off.

12. I was ill for 8 months after the operation. I got so many infections whilst in the Lister Hospital that it took me a while to fully recover. I received a huge amount of medication for the infections.

13. I did not work for the entire 8 months, and I was not paid, as I was a contractor at the time.

14. The physiotherapy was at Lister Hospital but I was living on the other side of GRO-C at the time. I could not drive to the Lister Hospital so I ended up paying for private physiotherapy. My ankle gets very stiff to this day.

15. I remember being told by the doctors at the Lister Hospital that I could no longer donate blood after having the operation. I had been a blood donor since the age of 18 and I used to donate blood twice a year. After the operation, I gave it two years before going to donate blood again.

16. I was happily married with my second wife, and earning a good living as an aeroplane engineer, we had our own detached property in the village and I had money in the bank.

17. One day I received a call from my wife whilst I was at work. When I spoke with her she explained that I had received a letter from the Blood Transfusion Service, which she had opened. She told me that something was wrong with me and I had an illness. It was at the time that AIDS was in the news and I immediately thought I had somehow or other contracted AIDS. I went home and we both read the letter together. My life changed from thereon in.

18. The letter from the Blood Transfusion Service stated that I had tested positive for HCV at my previous blood donation. They said that I could have contracted the infection from either sexual contacts or drug use. I was disgusted by the wording of this letter and completely staggered. I have never used drugs, I am fit and healthy, and I have never been promiscuous. I thought the letter must be a mistake, and I knew absolutely nothing about HCV.

19. I have been asked if I kept the letter? The answer is no, I now wish I had to show how wrong the letter was in its wording and the assumptions about how HCV is transmitted was written.

20. My wife, upon reading the letter, was extremely worried. She believed that I had been having an affair. GRO-C GRO-C GRO-C

21. My wife, soon after my diagnosis, said that she didn't want to be with me anymore. I had brought up her children as my own, and they still call me dad to this day. I always treated them as my kids, and did my best by them. She then decided that she didn't want to be with me.

22. I left the family home and went to live with my mum. I stayed on my mum's sofa all alone, worrying about whether I was going to die. I didn't want to sell the house as I wanted to avoid disrupting the kids' upbringing and schooling.

23. After the diagnosis I felt dirty and ashamed. I couldn't tell anyone, not even my close friends. I felt able to discuss it with my family, as we have always been a close-knit family. Their reaction was one of complete shock at how I could possibly have contracted the virus.

24. I was given very little information about HCV, including the risks of transmitting it to others. I did a lot of my own research and discovered that it was only transmitted by blood. There was a stigma associated with HCV and I felt isolated in dealing with the implications of my diagnosis.

25. I enclose as exhibit **WITN4414002** a letter from Dr P E Hewitt of the North London Blood Transfusion Service to my GP, Dr O'Toole, dated 05 March 1993. Dr Hewitt writes that I donated blood on 20 January 1993 'and on subsequent testing was found to have a positive screening test for antibodies to the hepatitis C virus (anti-HCV). This positive test has been confirmed in our Reference Laboratory.'

26. This continues: 'Mr Bamforth has been seen by medical staff at this centre and has been informed of the positive test result. He has given permission for us to write to you with his test results. As routine anti-HCV tests on blood donations were introduced only in September 1991 we are still accumulating knowledge about tests and the implications of positive results. Your patient has been informed that he should not donate blood again and must be considered potentially infectious for HCV.' The letter also advises that I should 'as a minimum have liver function tests performed in order to assess whether there is any evidence of liver damage.'

27. After my diagnosis I went to see Dr O'Toole, my GP at GRO-C. I was fortunate in that Dr O'Toole had recently researched HCV. As a result, he knew that King's College Hospital in London had a specialist department for treating HCV-infected patients. This was the best luck I could have had.

28. Dr O'Toole wrote to Professor A. Eddleston (Professor of Liver Immunology, Hepatitis Advice Centre, King's College Hospital) on 30 March 1993 (enclosed as exhibit **WITN4414003**). Dr O'Toole requested that Professor Eddlestone 'do some investigations to determine how much liver damage has occurred.' Dr O'Toole also wrote that 'his wife has subsequently left him', which shows that my (second) wife left me just three weeks after my initial diagnosis with HCV.

29. I was referred by Dr O'Toole to Professor Eddlestone at King's College Hospital. At my first appointment I asked them how I could have possibly contracted HCV. I explained that I had never taken drugs and I had always been faithful to my partners. I even asked my ex-wife to confirm that she did not have HCV.

30. At the appointment, the consultant asked me all sorts of questions. They then asked me if I had ever had a significant operation. I explained that around 5 years ago I broke my ankle very badly and I had to have an operation at the Lister Hospital. This thereafter seemed to be accepted as the cause of my HCV infection.

31. In September 1994 I was reviewed by Dr Nikolai Naoumov (Institute of Liver Studies, King's College Hospital). In a letter to Dr O'Toole date 09 September 1994 (and enclosed as exhibit **WITN4414004**), Dr Naoumov wrote that my 'liver function tests were entirely normal.' He added that I was 'entirely asymptomatic with normal liver function tests and therefore no treatment is feasible at the present.' However, if my liver function tests 'particularly serum aminotransferase show any abnormality, antiviral treatment with Interferon may be helpful to prevent a progression of his liver damage.'

32. I was reviewed at Professor Eddleston's clinic on 03 February 1995. I enclose a letter from Dr D.J. Ellis (S.H.O. to Professor Eddleston) to Dr O'Toole dated 03 February 1995 as exhibit **WITN4414005**. Dr Ellis wrote that 'He is sero-positive for Hepatitis C but has no real risk factors apart from surgery to a fractured ankle several years ago.' He

added that I 'may possibly develop cirrhosis in the future, although he may always remain asymptomatic. In addition there is research being done on Interferon for symptomatic Hepatitis C infection. However this would not be appropriate at the moment.'

33. Professor Eddleston wrote to my GP, Dr O'Toole, on 16 August 1995 (enclosed as exhibit **WITN4414006**). Professor Eddleston wrote that, for the first time, I had a 'significantly raised AST at 75. If this persists we really should proceed to liver biopsy to see if he is a candidate for Interferon therapy.'

34. I attended a hepatology outpatient clinic at King's College Hospital on 06 March 2000 following a liver biopsy on 08 November 1999. During the liver biopsy, I was in absolute agony. I have never felt pain like it in my life. Dr Stephen Gerred (Visiting Hepatology Registrar, Institute of Liver Studies at King's College Hospital) wrote to my GP, Dr A W G Savage, on 09 March 2000 (enclosed as exhibit **WITN4414007**). Dr Savage intimated the liver biopsy results that showed 'mild inflammation and moderate portal and early septal fibrosis.' He added that 'In view of the presence of fibrosis, combination treatment with Interferon and Ribavirin has been recommended. We are currently awaiting approval for treatment funding.'

35. I was reviewed by Dr Stephen Gerred and Dr O'Grady in the Hepatology outpatient clinic at King's College Hospital on 05 June 2000. Dr Gerred wrote to Dr Savage on 08 June 2000 (enclosed as exhibit **WITN4414008**). Dr Gerred wrote that I had 'transfusion acquired HCV infection' and that they had 'intended to treat [me] with combination Interferon and Ribavirin therapy in view of the early fibrosis. Unfortunately all funding for Hepatitis C therapy has been suspended pending a report from NICE (National Institute of Clinical Excellence).'

36. I was reviewed by Dr Roger Lee (Registrar to Dr S Norris and Dr J O'Grady, Institute of Liver Studies at King's College Hospital) on 11

December 2000. In a letter to Dr Savage dated 11 December 2000 (and enclosed as exhibit **WITN4414009**), Dr Roger Lee wrote that I had 'a history of transfusion acquired Hepatitis C virus…' He stated that 'we are awaiting a reply from the local health authorities who have been written to regarding their willingness to accept the cost of combination therapy.' He added that 'If funding was available we would offer him combination therapy with Interferon and Ribavirin.'

37. I started interferon and ribavirin combination therapy on 22 August 2001. I enclose as exhibit **WITN4414010** the consent form that I signed confirming my participation 'in a 200 patient expanded access trial in the UK of pegylated interferon alfa-2a (PEG-INF) monotherapy or in combination with ribavirin.' The course of treatment was to last for 12 months.

38. I remember my son drove me for the first injection of the treatment. It was a two-hour journey from GRO-C to the hospital, where I was administered my first interferon injection. They warned me that I did not want to be at home by myself that night.

39. On the way back and when I got home, I didn't feel too bad. I said to my son that he didn't need to stay here with me, so I told him to go home and I would be alright. Not long after he left, I started convulsing. My body reacted very strangely, and I was unable to control my movements. This only happened on the first occasion that I injected the interferon.

40. I self-injected the interferon into the sides of my stomach. This didn't overly concern me. The combination therapy had a significant impact on my energy levels. I couldn't do any real exercise, which affected me enormously as I am a keen cyclist. I was able to work part-time throughout the treatment, as I was able to walk around a barber's chair. However when it came to walking further than 10 yards, I became exhausted. I also suffered from terrible eczema and had itchy skin. I did

not particularly feel like eating, and I was nauseous whenever I did eat. This caused me to lose a lot of weight.

41. I remember that whenever I went out, I would put on fake tan so people would not think I was ill. If I was getting the train to London or elsewhere, I was praying beforehand that someone would offer me a seat as I was so physically exhausted.

42. I completed the 12 month course of pegylated interferon and ribavirin treatment. After completing the treatment, I was initially told that the treatment had been successful in clearing the virus. However, just a month afterwards I was then told that it had not worked. When I asked what the next steps were, the doctors told me that I could not start another course of treatment for a while after all I had just been through.

43. After several years I then underwent further treatment. I completed the second course of combination therapy in December 2008. This was again meant to last for 12 months. However, after completing the 12 month course, I was told that I needed another 6 month course of the treatment. I remember my wife at the time being devastated and frustrated that it had to continue. I think I received over 70 weeks of treatment.

44. The side effects of the second round of treatment were the same as the first, breathlessness and eczema.

45. In January 2009 I was finally told that it had been successful and that the HCV was now undetectable.

46. My current health is good. I have an annual check-up with my GP, who takes blood tests to check for the HCV and to ensure it has not returned.

Section 3. Other Infections

47. I have not had any infections other than HCV as a result of receiving an infected blood transfusion.

Section 4. Consent

48. I consented to the operation on my ankle at the Lister Hospital in 1986. I remember consenting to the operation when I was in the A&E department, though I was not informed that I would receive a blood transfusion.

49. I signed a consent form (enclosed as exhibit **WITN4414010**) to participate in the pegylated interferon and ribavirin treatment in 2001. The consent form included information on the treatment and the potential side-effects that I could face.

Section 5. Impact

50. When I received the letter from the Blood Transfusion Service in 1993, this was a significant turning point in my life. Up to this point, I had shown no signs of illness. Had I not been informed that I had HCV, I would never have known. In fact, the only illness I have felt during all of this has been as a result of side effects of the treatments.

51. I was absolutely disgusted by the way the letter conveyed this information to me. As I said earlier, I wish I had kept it now. I felt dirty and ashamed at being tarnished with the label of a 'drug user' or the suggestion that I was sexually promiscuous.

52. This letter was also responsible for the break-up of my second marriage. My wife opened and read the letter, and automatically assumed that I had been sleeping around. Within a few weeks she had

decided to leave me. As a result, I lost my house, my wife and daily contact with my children and step-children. This was devastating, all the while I was back living at my mum's house and not knowing whether I was going to die.

53. I come from a religious background, so to tell my family about the diagnosis was tough. They couldn't understand where it had come from or how I had contracted it. I did not understand it myself at first. I was not given any information as to how it was transmitted. It was only after undertaking my own research that I realised it was transmitted by blood. Thankfully my family are very close, and they were all very supportive.

54. I did not feel able to discuss the diagnosis with my friends. There was a stigma associated with HCV that meant I could not face telling them. I became very secretive and isolated as a result. I remember when I went back to hairdressing that I had to keep it quiet as I was worried no one would want me to cut their hair. I used to keep loads of plasters and tissues in my pockets in case I cut myself accidentally.

55. I was forced to give up my dream job as an aircraft engineer and production manager as a result of diagnosis. The industry itself had started to struggle and we began to experience staffing issues. However, my main concern was the constant cuts and accidents I had whilst at work which was putting my colleagues at risk of contracting the virus.

56. Fortunately, a friend of mine who ran a hairdressers shop offered me a job working for him. I started there on a temporary basis but ended up working there for 20 years. Had it not been for Covid-19 I would still be working.

57. I am definitely worse off financially than I would have been had I not been infected with HCV. Although I am a forward-thinking, positive person, I sometimes have a few 'what if' moments. I feel like I was

'turned over' with my pensions because of my dyslexia. Having worked for as long and as hard as I have done, I feel that I should have more savings. Although I am comfortable financially, I carried on working for longer as my pensions were not enough for me to live how I want to.

58. I have always been fit, healthy and hard-working. It was therefore very difficult for me during the treatments. The fatigue I endured made exercise nigh on impossible. I also lost a lot of weight as I lost all my appetite. I rarely felt like eating because it made me feel sick straight afterwards.

59. I am grateful to my family for all their support throughout the entirety of my ordeal. I feel fortunate to have such a loving and caring family, and my grandchildren are wonderful. I am grateful to have met my new partner, and we are both happy and content with our lives.

60. My eldest boy was worried sick about the fact that I was infected but also whether I would inadvertently infect his children.

Section 6. Treatment/Care/Support

61. My overall experience of Lister hospital has not been good. They gave me HCV and I also had a botched hernia operation in 2001 whereby I lost a testicle, and to add injury, I had to pay over £3000 to have the hernia repaired privately.

62. As shown in exhibits **WITN4414007-009**, my first course of interferon and ribavirin treatment was delayed due to issues with funding. This did not begin until August 2001, some 7 years after my diagnosis with HCV.

63. I was never offered any form of counselling or psychological support. I would not have accepted the offer of counselling even if it had been made available to me.

Section 7. Financial Assistance

64. I first heard of the Skipton Fund through a friend of my son. She had apparently been given infected blood as well, and had received compensation through the Skipton Fund. I do not know her personally, and this was communicated to me by my son.

65. I wrote to the Skipton Fund and received the application form by post. I completed the form with the assistance of my GP, Dr Michael Duggan of GRO-C Surgery in GRO-C. I applied to the Skipton Fund on 04 February 2009 and enclose a copy of the original application form as exhibit **WITN4414011**.

66. In my Skipton Fund application, Dr Duggan wrote under Section 4A- 'To confirm that infection most probably arose through NHS treatment'- that I had a 'surgical procedure for an internal fixation of a Potts 3 fracture' on 26 October 1986 at Lister Hospital, Stevenage. He wrote 'Unknown' under the section titled 'Do any records exist of this possible occasion of infection?' Dr Duggan also ticked that I received 'Plasma/FFP' and 'Whole blood or components'.

67. I applied to the Lister Hospital for my medical records pertaining to my operation in 1986. Lister Hospital wrote back stating that they did not have any records in relation to my treatment. I also applied to my previous GP practice in GRO-C, who said that all my records had been transferred to my new practice in GRO-C. My current GP, Dr

Duggan, reviewed all my records and could not find anything that proved I had a blood transfusion.

68. I received a reply from Nicholas Fish, Scheme Administrator of the Skipton Fund, on 20 February 2009 (enclosed as **WITN4414012**). Nicholas Fish returned my application form, writing that 'we are not able to progress any further your application at the present time. The doctor completing your form was unable to provide records that confirm you underwent treatment with NHS blood or blood products prior to September 1991 which is one of the requirements of the scheme.'

69. I then replied to the Skipton Fund with my application form and other medical letters stating that I had transfusion associated hepatitis C. I received a response from the Skipton Fund on 17 April 2009 (enclosed as exhibit **WITN4414013**). The Skipton Fund declined my application 'due to the lack of supporting confirmation that you were treated with NHS blood or blood products prior to September 1991 and that this was therefore the likely source of your infection with hepatitis C.'

70. In this letter, Nicholas Fish noted that the letters I enclosed with my application mentioned a past transfusion but wrote that 'in the absence of medical records this was presumably as a result of consultation between you and your doctor.

71. I knew there was an appeal process, however as someone with severe dyslexia this fell into the very difficult category, for this reason. I decided I couldn't go through the appeal process.

72. I was frustrated by the Skipton Fund's decision, as if I didn't get HCV from the operation at Lister Hospital, where else could I have got it from? I have never taken drugs, I have no tattoos, I have never been promiscuous and I have never received medical treatment abroad. The only possible way that I could have contracted HCV was through a blood transfusion during my operation at the Lister Hospital in 1986.

73. So there we have it, I lost my wife, my home and was infected with HCV. And to add insult to injury, Skipton said I did not meet their criteria, as there were no medical records. Lister said they hadn't got them.

Section 8. Other Issues

74. I would like the Inquiry to prove that I am not a dirty person. Through no fault of my own, I contracted HCV through an infected blood transfusion. The letter I received from the Blood Transfusion Service made me feel dirty and ashamed, and I want this to be conclusively disproven as the cause of my infection.

75. I'm not unduly worried about the fact I was denied any assistance from Skipton, they made their decision, I just want the Inquiry to get to the bottom of what happened. I tend to think that they knew the blood was infected, and this needs to be established. In many ways, I feel lucky that I didn't get AIDS.

76. As I have mentioned, I suffer from severe dyslexia, for the signing of my statement I have been provided sufficient time to read through and understand the content.

Statement of Truth

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

Signed GRO-C

Dated 9/10/20