Witness Name: Nathan James Pepper
Statement No.: WITN0446001
Exhibits: **Nil**
Dated: 17 December 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF NATHAN JAMES PEPPER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15 November 2019.

I, Nathan James Pepper, will say as follows: -

Section 1. Introduction

1. My name is Nathan James Pepper. My date of birth is **GRO-C** 1977 and my address is known to the Inquiry.

2. I am a delivery driver, and I live with my wife, our son and my two step-sons. 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

3. Prior to being interviewed for this statement, I spoke with my Mum about the very early years of my life for which I have no recall. Sadly, my Dad is no longer with us. As a child I had lots of bleeds and bruised very easily. My Mum and Dad took me to the doctors with a lump and bruise on the back of my hand when I was 9 months old. The doctor implied that my Mum had beaten me, though I was eventually diagnosed with severe haemophilia A, with 0% factor VIII in my blood.

4. My diagnosis with haemophilia was, at first, a surprise to everyone. There had always been a suspicion that the family had a history of haemophilia. My Nan's sister's son died when he was 3 years old. He had a head injury, and sadly died from a bleed to the brain. This was during the 1960s, and looking back my Mum's family now believe that he had haemophilia.

5. My Mum is a carrier of haemophilia. When I was diagnosed with severe haemophilia aged 9 months old, my parents decided that they should not have any more children. They believed that it would be tough enough for me, let alone to risk having another child that could have the disease.

6. My Mum recalls that they were called into the hospital to be told of my haemophilia diagnosis. After this I would regularly visit Leicester Royal Infirmary Haemophilia Centre whenever I had a bleed or a bruise.

7. I remember visiting the hospital often, sometimes every week, to be administered Factor VIII for a bleed in my joints. My ankles became very painful, and I still suffer with arthritis and difficulty walking to this day. I wanted to be 'normal', so if I had a bleed I would try and carry on without telling my Mum.

8. I was eventually allowed to go on home treatment. My Mum and Dad were taught by the hospital how to administer the Factor VIII to me. My Mum recalls that at some point I was given cryoprecipitate, but at some

point this changed to Factor VIII. I remember my Dad being better at administering the Factor VIII than my Mum.

9. To be allowed to administer Factor VIII at home was a godsend for the family. At the time we did not have a car, so my regular visits to the hospital would require a taxi journey there and back, whilst from time to time my Grandfather could drive us. I often missed school because of these visits, spending a lot of my childhood watching TV and resting at home. On one occasion I was forced to take two weeks off school when I had my tonsils removed.

10. I began to self-administer the Factor VIII when I was aged 7. I was shown how to inject the product into my veins, having been taught on an orange with lines drawn on to represent veins. I knew the Factor VIII product as 'freeze-dried plasma'. When I once asked where the blood came from, it was explained to me that it was collected from donors, where they would do something to the blood and finally separated the plasma from the blood donated.

11. Around 1983 or 1984, when I was aged 6 or 7, my parents were called in to the Leicester Royal Infirmary Haemophilia Centre. My Mum recalls that this was a face-to-face meeting with Dr Woods on level 2 of the Balmoral Building at the hospital. She also remembers a Dr Mitchell and a nurse called Carol Martin from that time, who looked after me for two years. At the meeting with Dr Woods, they were told that I had been given a batch of Factor VIII that was infected with HCV.

12. My parents were told that I had been tested for HCV and these results showed that I was positive. My Mum was not given a lot of information about what HCV entailed, and was not told about any risk of exposure to infection. I was not given any form of prognosis, and my parents were told there was no cure or treatment available for HCV. My Mum recalls that when she left the hospital, she looked at my Dad and said 'What do we do now?'.

13. After my diagnosis with HCV, life carried on pretty much as normal. I went on a holiday organised by the Haemophilia Society when I was about 8 or 9. The group of kids were all haemophiliacs and we were kept under proper supervision, with doctors and nurses coming along with us. I took prophylaxis Factor VIII prior to going on the trip. I remember this vividly as it was an injection from a huge bottle of Factor VIII with a long needle. The clotting agent took half an hour to dissolve. I learned some years later that the majority of the kids I went on this holiday with contracted HIV and died as a result of the infected blood products they received.

14. It was not until my teenage years that I began to go for more regular check-ups at clinics. I did not see a liver specialist until my late teenage years, though I had liver function tests and blood tests for HIV every 6 months. I was told that I was lucky not to have received a batch of Factor VIII infected with HIV.

15. Throughout this period, I did not experience any real symptoms as a consequence of my HCV infection. It felt like it had been brushed under the carpet. Then, when I was aged 17 or 18, I spoke to Professor Pasi at the Leicester Royal Infirmary who explained the options available for treatment. He discussed liver transplants and a new treatment called combination therapy, involving Interferon and Ribavirin. I consequently began this combination treatment aged 18 in 1995.

16. This first course of treatment involved self-injecting Interferon every other day, in addition to taking a Ribavirin tablet once daily. It took just two hours for the side-effects of this treatment to kick-in. The Interferon injection felt like I was injecting a dose of flu. Although the side-effects got a bit easier over time, my then-work as a minibus driver was affected by extreme episodes of fatigue and low-mood. I tried hard to get into work when I could, but this was often immensely difficult.

17. This treatment was stopped after three months. Although my viral load had shown signs of decreasing throughout the course of the treatment,

it did not disappear entirely. By the third month my viral load had begun to increase again. The Haemophilia Centre phoned me and said that they were stopping the treatment after the 12th week.

18. My second course of treatment began when I was around 25, approximately 7 years after the first course. This was again a combination of Interferon and Ribavirin, though at higher dosages. I took an injection of Interferon every other day, and a Ribavirin tablet daily. I believe this was an established treatment and was not described to me as a trial. After the first course 7 years earlier, I went into this treatment with a lot less confidence of it working. I was much less compliant with the medication, and became ill-disciplined as regards taking the tablets. During this 6-month course I was forced to go onto antidepressants due to my persistent low mood and depressive episodes. Ultimately, my viral load showed little sign of improving, and I stopped the treatment after 6 months.

19. The third course of treatment began in 2012, when I was aged 35. This treatment was a combination of Pegylated Interferon and Ribavirin, in the form of six tablets taken daily. I suffered from the same flu-like symptoms, and some minor hair loss. I was again prescribed antidepressants (Citalopram) after a month, having experienced a repeat of the depression that I suffered during my first treatment.

20. On this occasion, non-compliance with the treatment was not an option. I was significantly more disciplined this time, principally because of the birth of our son three years earlier. After 6 months of treatment, my viral count went from millions down to 18,000. However, in the 6th month my viral load shot up significantly once again. Having been so close to clearing the virus, and seeing that I had made significant progress, I was devastated to be told that it had not worked in clearing the HCV.

21. After the disappointment of this latest failure, and having endured such extreme side-effects once more, I remained on the antidepressants for around a month. I then decided to go cold-turkey and stopped taking the

antidepressants immediately, which had a big impact on me. I encountered terrible mood swings, and would get angry with everything. I felt like I was being pulled in different directions, and this continued for a further two months.

22. In early 2013 I was diagnosed with bowel cancer. I first began to experience some symptoms in late 2012. Having visited my doctor, I was referred to the hospital where they performed a flexible sigmoidoscopy. As the camera bent around, I could see a dark shape on the screen directly in front of me. I asked the doctor if it was a tumour, and he replied that he was unsure. When I returned to the hospital soon after, it was confirmed that they had found a tumour.

23. I underwent bowel surgery soon afterwards, following which I had a colostomy bag for 6 months. This was then reversed. Throughout this period, I was given regular Factor VIII prophylaxis. The tumour was successfully removed and I am now in remission. I subsequently found a new job in September 2013 with my best man.

24. This lasted for around two years until, in 2015, I was diagnosed with metastases in my liver. I was told this was secondary to the bowel cancer. At this time, the doctors found that I had cirrhosis of the liver, which was a direct consequence of my infection with HCV. I again underwent surgery, and the tumour on my liver was successfully removed.

25. Prior to my diagnosis with liver cancer, I had a consultation with Dr Bell, a liver specialist at the Leicester Royal Infirmary, who explained that I may be eligible for a new HCV treatment. This was subsequently put on hold once my liver cancer had been diagnosed. Then, on 30th October 2015, my metastases was cleared, and I was to be considered for this new treatment.

26. Dr Bell told me that, since I had cirrhosis of the liver, I was eligible for a new treatment with Harvoni and Ribavirin. This started in 2016 and

involved taking 1 Harvoni tablet and 6 Ribavirin tablets daily. I did suffer from fatigue and low mood, for which I went back on to antidepressants. However, the symptoms were not as severe as the previous three treatments.

27. After 2 weeks of the Harvoni and Ribavirin treatment I was told that I was 'negative'. The HCV was not detectable after two weeks, and this remained the same every week until the end of the 3-month treatment. After 6 months, this was still negative, and again at 12 months from the beginning the treatment. I was told that I have a non-detectable viral load. I still have cirrhosis of the liver, though I am told that this should not get much worse now. I am now HCV negative and in remission from cancer.

Section 3. Other Infections

28. I do not believe that I received any infections other than HCV as a result of being given infected blood products.

29. I have received a letter stating that I was exposed to vCJD, though this cannot be confirmed by testing.

Section 4. Consent

30. I do not believe that my parents consented to me being tested for HCV when I was aged 6/7. Although I had regular blood tests when I went to the hospital, I do not believe that I, or my parents, were told that I was being tested for HCV.

31. Not until after I was diagnosed with HCV did I consent to being tested for HCV.

32. I consented to all four courses of treatment in respect of my HCV infection.

Section 5. Impact

33. I have lived with haemophilia for all of my life. I have an attitude that I have to get on with things, and this became a normal process for me from a young age. I have endured periods of depression because of the treatment and also the hopelessness that I felt about my HCV infection. When my treatment failed on each of the three occasions, this would add to my sense of defeat and make me feel even more down.

34. Meeting my wife, and marrying her in 2005, changed my entire outlook. I have a great relationship with my two step-sons, from my wife's previous marriage, and we have a son together born in 2009. My wife is a healthcare professional and has been a terrific help to me throughout the entirety of this ordeal. I told my wife about my HCV infection within a week of us meeting. Whereas I am used to challenges and difficulties, this was a whole new thing for her. She has been terrific and we have been a great team in tackling my health problems together.

35. The impact on my infection has been different for my parents. My Mum was the carrier of the haemophilia and took me to the hospital where I was given the infected blood products. This has been difficult for her to deal with, though of course it is not her fault at all.

36. When we told my Mum about our intentions to have a child, she was concerned. She was initially against the idea because of the worry of having a child that carried the haemophilia gene onwards. When my wife was pregnant, we went for a scan to check the baby's sex. The nurse was almost inquisitorial, questioning why we wanted to know. When we told her she showed no understanding about haemophilia, and was ignorant of our concerns. We were relieved to learn that our baby was a boy as it meant the carrier gene was gone from the family.

37. I believe that my/our social life has suffered as a result of my HCV infection. During my courses of treatment, I was advised not to drink

alcohol. My friends would go out together for a drink whilst I was at home suffering with the side-effects of the medication. When the treatment stopped I continued to abstain from drinking, and whenever we went out with friends I had to explain to others why I wasn't having a drink.

38. It is difficult to make decisions about future-planning for my family as I cannot get life insurance. This is always in my consciousness, and I worry about the security of my family and my children's futures.

39. In general, I have not been subject to any real stigma because of my HCV infection or my haemophilia. I was left out of certain activities and events whilst at school either because I could not run, due to my ankles and pain in my joints, or because of the teacher's concerns about me cutting or bruising myself.

40. On one occasion when I was aged 13 or 14, a girl at school asked me if I had AIDS in front of the whole classroom. She said that haemophiliacs were being diagnosed with HIV and knew that I was receiving injections whilst at school. Aside from this particularly embarrassing incident, I was not subjected to any significant degree of stigma unlike as I understand, other victims of infected blood and Factor VIII have experienced.

41. My wife is unable to donate blood because of her relationship with me. As a healthcare professional, she was tested for HCV, for which she is negative, and she was tested again whilst she was pregnant with our son. We were forced to use protection during my treatment with Ribavirin, having been told that my wife would have to have an abortion if she got pregnant due to the effects of Ribavirin on the baby.

42. Whenever I went to the dentists for a check-up I was always the last appointment of the day. I spent lots of time hanging around in hospitals and dental practices as the equipment they used on me had to be separate from the usual operating equipment. My forms often contained bold yellow stickers saying 'biohazard', and some surgeries were even

cancelled as they did not have certain equipment set aside only for me, despite my having gone nil by mouth all day.

43. I have cirrhosis of the liver, and this will not get any better despite having cleared the HCV. I am constantly worried that this could flare up into something worse further down the line, particularly with my history of cancer. I am concerned about what could happen to my liver, which plays on my mind and makes me feel guilty whenever I have the odd drink.

Section 6. Treatment/Care/Support

44. I have not had any difficulty in getting treatment for HCV infection. My wife is aware of other people that have experienced significant problems in receiving the Harvoni treatment. As a healthcare professional, she heard stories of people that were HCV positive but unable to access the Harvoni treatment as they had not yet developed cirrhosis of the liver. Because of the high cost of a course of Harvoni treatment, we have heard that some people were forced to buy the medication from Egypt where it is much cheaper. They would then attend a clinic in the UK that was willing to treat these patients with the Harvoni and monitor them during the course of treatment. I cannot say personally whether this is accurate.

45. I have not been offered any form of counselling or psychological support in consequence of being infected with HCV from infected blood products.

Section 7. Financial Assistance

46. I applied for a Stage 1 Skipton Fund payment in 2004 and received £20,000. This was paid on the condition that I sign a document stating that I would not take them to court and pursue any action against them.

I was also told that I would receive a further £25,000 if I died which, as I was not married at that time, would go to my parents.

47. In 2015, soon after I was diagnosed with cirrhosis of the liver, a haemophiliac friend of mine informed me of a change to the payment system for those infected by infected blood products. I looked up the payments available and applied for a Stage 2 payment from the Skipton Fund. In support of my application I requested a liver biopsy from the surgeon due to perform the surgery on my liver metastases. He was happy to do this, and I used the results as further evidence of my cirrhosis as a result of my HCV infection.

48. In response, I received a Stage 2 Skipton Fund payment of £50,000, alongside monthly payments of around £1300 a month. This has now increased, as of July 2019, to around £2300 a month. I also receive a winter fuel allowance of £500 a year.

49. I have received Disability Living Allowance (DLA) from the age of 16 because of the swelling in my ankles caused by bleeding in the joints and making it harder for me to get about. This was temporarily stopped in February 2019, despite being promised that I would receive it for life. I had a 'Motability' car, which I had to return when the payments ceased. I did receive a 'transition' payment of £2000, to soften the financial impact of suddenly losing the DLA. However, under the Universal Credit reassessment it was then reinstated 2 months later, though the transition payment was taken into account.

50. I am unable to get life insurance because of my HCV infection and medical history. The last time I applied, I was offered £30,000 cover for £250 a month, which is just ridiculous. I am also unable to get a mortgage; although I declared that I was not working and received £18,500 a year from the Skipton Fund, this was not accepted due to a lack of documentation. I obtained a special letter from the Skipton Fund saying that these payments would last 'for the foreseeable future'.

Regardless, my application for a mortgage was refused as this did not amount to declaring a regular wage.

Section 8. Other Issues

51. I believe that this entire scandal should have been avoided. It is scary to think what has happened. I feel that the authorities have played a game of Russian roulette with haemophiliacs, when they knew that the people donating blood in US prisons were likely carrying infections. I do not understand why they did not test the blood, knowing where it came from, and particularly knowing that it would be used to treat children with haemophilia.

52. I felt that I was just unfortunate to have been given the HCV infection via a bad batch. It was only when I got older that I realised what had happened and I started to ask questions as to how and why it had ever been allowed that the blood was not ensured as being safe.

53. I feel that this has been an experiment, and that I have been experimented upon, because of the extent of the negligence that has taken place. I want the people responsible to admit they were wrong and to be held accountable. An apology would mean nothing now; this should not have happened in the first place, and lessons need to be learnt to ensure that nothing like this ever happens again in the health service.

54. I want justice. It is not about the money or compensation, though I believe that payments should be equal across the whole of the UK. If they do choose to compensate us victims properly, we also need a means of insuring ourselves. If something happened to me, my wife and kids would not be protected as I am unable to get life insurance. Some sort of cover is required so that victims do not have to worry if something happens to them in the future.

55. I am grateful to the Inquiry for the chance to have my voice heard.

Statement of Truth

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

Signed GRO-C

Dated 17.12.2019