Witness Name: Graham Berwick
Statement No.: **WITN0303001**
Exhibits: **WITN0303002 -**
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRAHAM PAUL BERWICK

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 30 January 2019.

I, Graham Paul Berwick, will say as follows: -

Section 1. Introduction

1. My name is name is Graham Berwick. My date of birth is **GRO-C** 1958 and my address is known to the Inquiry. I am not married and I do not have any children. I am currently employed as an Assembler for an electronics company.

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

3. 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.

Section 2. How Infected

4. I was diagnosed with severe Haemophilia A at Great Ormond Street Hospital when I was 4 years old. My condition is considered severe because I have less than 1% of normal Factor VIII activity levels in my blood.

5. When I was diagnosed, the hospital recommended that my parents and I join the Haemophilia Society and we became members in 1962. My younger brother, Gary Berwick, is seven years my junior and also has severe haemophilia. As a result, our treatments and appointments were almost always undertaken together.

6. As a child, access to treatment was very limited and I would often just have to "ice and rest" any bleeding at home. For serious bleeds, I would have to attend the paediatrics ward at Crawley Hospital and receive a blood transfusion. It was rare that I would actually need to attend the hospital (about once a year) and I estimate that I would have received two or three blood transfusions as a result of serious bleeds.

7. When I was about 8 or 9 years old (1966 or 1967), Crawley Hospital began offering treatments using cryoprecipitate, although the treatment was limited to serious bleeds and I would only require cryoprecipitate about once a year.

8. Between the ages of 16 and 20, I was transferred to St George's Hospital in Tooting ("St George's"), as I was too old to continue being treated in the paediatrics ward at Crawley Hospital. I would attend St George's about once a year or so for treatment with Factor V111, and to start home treatment a few years later. I was dealt with by my clinician at the time, Professor Flute.

9. At about the age of 24, Gary and I were seen by Dr Bevan, a new clinician at St George's. Dr Bevan became our regular clinician and immediately changed our home treatment from treating any bleeds with Factor V111 at home, "on demand" to prophylactic treatment. This consisted of regular doses of Factor V111 at home to prevent bleeds.

10. I was first placed on home treatments at about the age of 22. At this time I would treat any bleeds on demand. It was not until a couple of years later that I went over to prophylactic treatment, which consisted of a set amount of Factor V111 given three set days of the week. The science at the time suggested that haemophiliacs of my age (I would have been about 24) and older would not receive any benefit from prophylactic treatment. I believe that one of the main reasons I wasn't placed on to prophylactic treatment immediately was due to product availability and the associated costs, so the treatments were initially reserved for younger haemophiliacs.

11. It was still quite rare for me to actually use the home treatments, as I would only need to treat myself once or twice a year. When I did use the home treatment, I would typically use about 2,000 international units (which is equivalent to about 7ml of Factor VIII when mixed).

12. I remember that one day in my mid-twenties (after I commenced the home treatments), I began feeling really ill at work. I started to feel extremely tired throughout the day, regardless of how much sleep I would get. I didn't think too much of it at the time and I continued to work, however with the benefit of hindsight, I anticipate that this is when I was infected with HCV.

13. Gary and I would regularly attend the Haemophilia Clinic at St George's to meet with Dr Bevan for a bi-annual check-up. When I was about 24 or 25, this was around 1983 or 84 but it could have been later. Dr Bevan informed us (during one of these check-ups) that the hospital had done some tests on our blood and the results showed that I had been infected with HCV, and Gary had been infected with HCV and HIV.

14. This diagnosis came as quite a shock to us both. We weren't aware that the hospital had even undertaken those tests on our blood (they did not seek our permission to do so), however this is not something we considered until much later.

15. When Dr Bevan informed us of the diagnosis, he was quite direct and very straightforward with us both. Dr Bevan was the kind of Doctor that wouldn't side-step an issue like this - it was his style to be up-front and discuss things with you straight away, but he would always be working in your best interests. After he had told us about our diagnosis, Dr Bevan gave us enough information to understand the basics of HCV and told us that we had to be careful about what we did, to ensure that we didn't infect anyone else.

16. Dr Bevan made it really clear that we should inform our medical professionals that we had HCV, particularly our dentist. He said that there was a high risk of infection through the transfer of bodily fluids or blood-to-blood contact, so it was imperative that the dentist was aware. He also stressed the importance of making sure you immediately put plasters on abrasions and practice safe sex. These days, you would receive a lot more information than that, but at the time, I think the information we received was sufficient.

17. Whilst it was never confirmed, I believe that I was infected with HCV as a result of using infected Factor VIII home treatments. The home treatments were an American product (it said so on the box), which I commenced using around 1982. I believe that the blood transfusions I received as a child were taken from British donors (which should have been screened) and any cryoprecipitate that I received thereafter was also British.

18. When I began using the home treatments, I kept meticulous records of the dosages and batch numbers. The home treatment packages came with a small booklet to record the details of each dose, so that you could take the booklet to the clinic and they could have a look at what you have taken.

I recall a nurse at the clinic commenting on how thorough our records were when we returned them to St Georges.

19. I always considered it strange that despite always using the same treatments as my brother, our infections differed. As I mentioned above, Gary was also infected with HIV (in addition to HCV). Curiously, there was only one batch of treatments that we did not share. We have no confirmation as to whether that particular batch was infected with HIV, however we speculate that this may have been the case.

Section 3. Other Infections

20. I do not believe that I have received any infection other than HCV as a result of using infected blood or blood products.

21. After being diagnosed with HCV, I was continually tested for HIV for approximately 15 years. I believe that this was because Gary was infected with HIV and I wasn't. I told the hospital staff about how Gary used a batch of Factor VIII that I didn't and I thought that may have caused the HIV infection, however no one seemed particularly interested. I've always just assumed that there must be something in my body that protects me against HIV infection.

22. A few years after being diagnosed with HCV, Dr Bevan told us that they had done some tests on our blood to check for Mad Cow Disease. I don't recall them asking for permission to do this, I just recall being asked whether or not we wanted to know the results. Nonetheless, Gary and I both told Dr Bevan that we wanted to know the results and he said "good - neither of you have it".

Section 4. Consent

23. As I mentioned above, I do not believe that St George's sought permission (from either Gary or I) to test our blood prior to our diagnosis or to test for Mad Cow Disease.

24. With the exception of testing my blood without permission, I do not believe that I have been treated without my consent or tested for the purpose of any research.

Section 5. Impact

25. Despite being diagnosed with HCV in my mid-twenties, I feel like I have been lucky when I consider the impact that it has had on my life in comparison to my brother and other members of the Haemophilia Society.

26. From a physical perspective, the general tiredness and lack of energy are the main issues that I have to deal with on a regular basis. When I first started feeling the side effects of HCV in my mid-twenties, I noticed that regardless of how much sleep I was getting, I would never feel refreshed after waking in the morning. Other people have it a lot worse than me, but as I get older I am feeling increasingly drained.

27. I was never a particularly sporty person, however I have always worked in positions where I am required to be physically active. There have been many times in my life when I feel quite ill or low on energy and still gone into work, when I probably shouldn't have. Some days I feel horrible, but you just have to carry on.

28. I do not think that being infected with HCV has taken a toll on my mentality. I have always taken the approach that there is nothing I can do about it, so why should I sit around and be defeated by it? I always worked from the perspective that I will just continue to carry on with my life. Sometimes there are days when I wonder why this has happened to me, but those thoughts disappear with age.

29. I do hold some resentment about the fact that my brother was infected with HIV and I wasn't. It really hit me one day when I was in the car with my father on the way to the markets at Haywards Heath. I was about 32 years old at the time and Gary was soon to be married. My father said that he was so glad Gary was getting married, because you could never be

sure about what was going to happen with his health. That comment really made me aware of the fact that there was a real possibility that Gary could die.

30. Our infections obviously had a devastating effect on our parents and sister. Since I was a small child our parents have continued to help Gary and I get the most out of our lives. They both feel the pain that Gary and I endure every day and there is no question that it would take it out of them too.

31. When I was about to commence primary school (age 5 or 6) my GPs warned my parents about sending me to a "normal" school and suggested that I attend Lord Mayor Treloar College. They basically considered me to be disabled because after all, I did have a serious life threatening disease.

32. Despite the advice of my GPs, my parents did not send me to Lord Mayor Treloar College. My parents had a discussion with Mrs ~~Bartworth~~ BARKWORTH who was the headmistress of both GRO-C and GRO-C GRO-C in GRO-C, who spoke with the board of governors and they allowed me to attend both schools. After finishing at GRO-C and GRO-C, I went on to attend GRO-C and then GRO-C. As before my parents had to speak to both Headmasters who then spoke to their board of governors before I could attend these schools. I have to take my hat off to all four schools, they took us on knowing we were Haemophiliacs, other people knew we had it, we didn't hide it or make a big deal out of it, we just lived a normal life as our parents and we wanted.

33. Growing up at school I never felt anything other than normal. At Secondary school, there was a fellow student with muscular dystrophy and another with a disability - the teachers and students were just accepting of each other. The teachers saw us as just another student to be taught. Generally, the other students wouldn't mention my Haemophilia but occasionally, you would get called names

34. As an adult, I don't think that having HCV has had a major effect on my social life. I am not a big drinker and I don't really go out partying. Sometimes we head out for a meal and I always hope that the cutlery is going to be washed thoroughly - I'm constantly aware of the risk of infecting other people. Infecting another person is my biggest fear. I have the same fear when I go to the dentist, I always hope that the equipment is cleaned properly.

35. I haven't had many relationships in my life. The thought of having to tell someone about my infection is probably part of the reason why I haven't pursued it. I've just always thought that I'll carry on as I am and keep it to myself. I would find it incredibly hard to discuss this with someone if I were to have a relationship with them, as the possibility of rejection would be a horrible scenario.

36. A similar fear has existed in the relationships that I have formed with work colleagues over the years. A lot of people know that I have Haemophilia (and they don't really care), but not many people know that I have HCV. A while ago, one of the guys at work asked about my Haemophilia and I was worried that it would lead to a discussion about HCV, as I had no idea how he would react if I told him. When people start talking about Haemophilia, I'm always nervous that it will lead into question about HCV. I'm a truthful person and if someone were to ask me, I would tell them. The main concern that I have is about how the person would react because there is a possibility that they would be concerned, upset or angry that I hadn't told them, particularly because I had worked with them for so long. Other people might brush it off, but it is still hard to figure out what their reaction might be - would they be angry that I haven't told them? Or upset that I could have exposed them to a risk of infecting them or their families? There is such a lack of knowledge about HCV that people just don't know how to react.

37. In the early days, there was a clear stigma attached to HCV (and HIV). I remember in the paper there was even a small campaign to have people

with HCV and HIV locked up! I remember thinking about the possibility of Gary and I being locked up simply because we were infected. I feel that today there is still a stigma attached to HCV, as people immediately think that they are at risk of being infected when they find out. There really needs to be increased education about what HCV actually is.

Section 6. Treatment/Care/Support

38. About a year after I was diagnosed with HCV (1983 or 1984), St George's asked if I wanted to take part in a trial treatment using Interferon. At that stage, they had achieved some success in the past however it was still quite new. Gary and I both took part in the trial, however I only lasted two weeks. The trial was supposed to run for six months, but was extended to twelve and Gary successfully completed the whole trial.

39. The trial had a devastating effect on my physical and mental health. It made me terribly sick, angry and aggressive, which is entirely inconsistent with my personality. Despite only taking Interferon for two weeks, it took a whole year to clear it out of my system. At that time, the side effects of my HCV weren't too bad, so Dr Bevan decided to monitor my condition by undertaking liver scans every couple of years. Generally, those liver scans showed no real change in my condition.

40. Given that I did not want to take Interferon, there weren't really any alternative forms of HCV treatment available to me. I do not think that I have faced any difficulties in accessing treatment - Dr Bevan knew that I wouldn't take Interferon, so I think that they just didn't offer me any further treatments as they all contained Interferon. I think they offered me everything that they could, but we simply continued to monitor my liver with scans.

41. In my mid-twenties, I commenced ~~daily~~ prophylactic home treatments. I have continued to use these treatments ever since and I currently use a brand called "Elocta". Prior to this, I used a brand called "Helixate". There

were other brands that I used before Elocta and Helixate, however I cannot remember their names.

42. As technology improved, I started getting regular fibroscans, which allow you to see inside the liver rather than just looking at the outside of the liver as you would with a normal scan. The fibroscans have shown that my condition is getting worse, as there is a cyst in my liver which I have had for a long time. In the past couple of years, the fibroscans have shown that my liver is reaching a point that will soon require treatment, otherwise there is a high risk of developing liver cancer.

43. I was really only advised of the risk of contracting liver cancer in the last three to four years, however I had already surmised this in my head by the time I was informed of it.

44. Within the last ten years, new treatment has become available that does not contain Interferon. My current doctor at St Georges, Dr Austin, has recommended that I undertake this treatment due to the condition of my liver. I am due to return to the clinic in April 2019 and I am considering commencing the new treatment then.

45. I have never really been offered any psychological support, however I do not think that I have really required it. The support that I received from Dr Bevan generally answered any questions I had and I felt comfortable discussing my condition with him.

Section 7. Financial Assistance

46. In approximately 1990 or 1991, I received a one-off payment of £20,000 from the Skipton Fund. I found out about the Skipton Fund when I received a letter in the post, which enclosed an application form. I am unsure how the Skipton Fund obtained my details, but I anticipate that this may have been through the Haemophilia Society.

47. I was initially quite reluctant to submit the application, because families that had already lost someone were not entitled to receive any money as the infected person had already passed away. I was eventually convinced by my family to apply for the money, and I was glad to see that the rules were eventually changed to accommodate families that had lost people due to infection.

48. Before submitting the application to the Skipton Fund, I had to have it signed by Dr Bevan. Dr Bevan seemed a bit annoyed by my request, which simply may have been attributed to the additional work involved in filling out the form, or alternatively, the possibility of any implication as it was his signature on the form. Whatever the reason, I cannot be sure.

49. In any event, Dr Bevan completed the form and I received my payment. When I received that payment, I thought that because it was an unconditional one-off payment, it meant that they're not going to pay you anything else and that you could not make a claim against the NHS. I thought that it was an admission that they had infected us and this was their way of compensating for it.

50. A couple of years ago, I came home from work and I received a call from someone at the Skipton Fund (I think his name was Mr Fisher). He asked about my details and I told him that I thought the Skipton Fund had been wound up. He informed me that they were still operating and said he was calling to ask if I had received my payment. I was somewhat confused as I had received the payment over 20 years ago, but he told me that they were just going through the process of updating their records.

51. Sometime around 2010, I received a letter from the government which said they intended to pay some money to people with HCV. After I read that letter, I figured that you had to more or less be dying to actually get any money. About three years ago, I received a backdated payment of approximately £3,000 and after that I received monthly payments of £333 (tax free), in addition to a £504 winter fuel allowance.

52. Aside from the payments that I have set out above, I am unaware of any other money that I am entitled to. I'm not really aware of any information about other finance options and I haven't received any material from the Haemophilia Society.

Statement of Truth

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

Signed GRO-C

Dated 18.TH. APRIL.2019.