Witness Name: Simon Payne
Statement No: **WITN5483001**
Exhibits: **WITN5483002-04**
Dated: 30/03/2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SIMON PAYNE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 March 2021

I, Simon Payne, will say as follows: -

Section 1. Introduction

1. My name is Simon Payne. My date of birth is GRO-C 1957, I live in GRO-C West Sussex and my full address is known to the Inquiry. I have been married for 40 years and I have 2 sons who are 25 and 23 years old.

2. I started off working as a butcher because I was unaware that I had haemophilia. I left the trade partly because of my bleeding disorder and because of the effects of supermarkets on local trade at that time. I moved to Beechams (which later merged with GlaxoSmithKline) and remained there for 36 years.

3. I intend to speak about my infection with the Hepatitis C virus (HCV), which I believe I contracted as a result of being given blood products to treat haemophilia.

4. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment that I received and the impact it had on my life.

5. 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

6. I am one of 6 children and I have 4 brothers. GRO-C GRO-C GRO-C As a child I knew that I had a bleeding problem, but I was never formally diagnosed. When I had teeth extracted, I bled through 2 pillows and onto the mattress. On one occasion following an extraction, I could not stand up so my father put me on a trades bike and took me to Worthing Hospital. A wedge of bandage was poked into my gum and the doctor used his pen to push it down. I also had knee bleeds playing football and I suffered with bad bruising.

7. I was diagnosed with haemophilia at the age of 20 by Dr Rodan at Worthing Hospital. GRO-C was working at a slaughterhouse and an axe fell on his thumb. The cut would not stop bleeding, so GRO-C and I were called down to be tested for bleeding disorders.

8. As soon as I was diagnosed I received Factor VIII for numerous bleeds and received a lot of the product in the late 70s, throughout the 80s and 90s.

9. I regularly went to Worthing Hospital for check-ups, tests and to meet with a female Haematologist, Dr O'Driscoll. The appointments were always very informal and she would ask how I was.

10. In my early to mid 30s, I started feeling unwell with fever like symptoms and I began to experience discomfort in the right side of my stomach. I could not lay on my right side because my liver was swollen and when I got out of bed the pain was horrendous from just putting my feet on the floor. My ankles were sore all of the time. I was regularly going to the Haematology lab at Worthing Hospital during

this period and I had chats with the haematologist where I described the pain in my liver and abdomen. I experienced the symptoms for the best part of 3 years.

11. I am sure that I saw Dr O'Driscoll two or three times and at every appointment I told her that I was washed out, my joints hurt and my liver was swollen. She would ask me how I was and I would describe my symptoms but no further investigation was done.

12. I was diagnosed with HCV in the mid 1990s (I would have been 35/36 years old) by a hepatologist from St Thomas's Hospital, who was a locum at Worthing. I believe it was just a slip of the tongue on his part and he presumed that I already knew about the infection. He was surprised that I had not been informed. I would have been none the wiser, had he not have mentioned it and I was shocked that no one had ever said a word.

13. I continued to receive Factor VIII for internal and muscle bleeds.

14. What hurt me the most was that no one said anything and I was disgusted about how I found out about my infection. No-one ever sat me down and told me I had been infected. My wife and I were expecting our first child at the time, so I was worried and angry over the fact that I could have infected my wife and our unborn child.

15. No medical professional has ever sat down and explained any risks of the virus and provided any infection management. I have not been informed of any dietary requirements.

16. GRO-C GRO-C. I already knew that I was infected, but the last thing I wanted was for anyone else to contract the virus. Neither of my sons have haemophilia.

17. GRO-C. I knew that they did not receive Factor VIII in the volumes that I did and not until the early 2000s. GRO-C only received it once for dental treatment.

18. To confirm, I have never used intravenous drugs. I do have a tattoo on my right arm which was done when I was 16. I have mentioned this to my GP and Haematologist, but they confirmed it would not be the source of my HCV infection. Most of the tattoo has disappeared because it was not done deep enough.

Section 3. Other Infections

19. I have not contracted any infection other than HCV as a result of being given contaminated blood. Retrospectively, I found out that I was tested for everything and anything.

20. I was tested for vCJD about 10-12 years ago at St Thomas' Hospital. I was asked if I wanted to be informed of the result, and I chose not to know.

Section 4. Consent

21. I was not informed that I was being tested for HCV. I underwent regular blood tests at the hospital, but as far as I was aware this was to check my haemophilia count. No medical professional ever said any different. As mentioned earlier I was shocked when the locum doctor mentioned in passing during my hospital appointment that I had HCV.

Section 5. Impact

22. In the late 1990s I was asked to go to St Thomas' Hospital for a check-up and blood test because they supplied all of the Factor VIII that I had been using, so it was suggested that it would be better for me to go there rather than Worthing Hospital. My liver was scanned and I still had a trace of HCV in my system. The swelling in my liver had gone down and I felt more comfortable. The doctors decided that the best course of action was for my immune system to carry on suppressing the virus. At this stage I no longer experienced the feverish symptoms and the pain in my joints eased drastically. I was not offered any treatment for my HCV.

23. The liver scan detected cirrhosis in certain areas of my liver due to scarring from the HCV. A certain area of my liver was damaged and as a result I do not produce Vitamin B12. I receive injections every 12 weeks at my GP practice, but I find that from week 9 onwards my memory gets worse and I get dates mixed up. I will require the injections for the rest of my life.

24. In 2009 I was told that the viral load for HCV was minimal and that it was best to let my immune system suppress the virus.

25. They carried on scanning my liver at St Thomas' – initially every 6 months then annually and now every 2 years. Blood samples are taken at each appointment and a liver function test is carried out. I also see the physio. The last scan I had on my liver was 3 years ago – I had an appointment scheduled for the 5 February 2020 but I had to postpone because of a family matter. It was then cancelled because of the pandemic and lockdown.

26. A liver biopsy has never been carried out because of my bleeding disorder.

27. I now go to St Thomas' every year for a routine appointment and I no longer receive any care from Worthing Hospital. Everything at St Thomas' is on one floor and can be done in one appointment.

28. I have never been offered any treatment and I just accepted this because I was pleased that the symptoms were finally easing. I was told that my viral load is minimal because my immune system has suppressed the infection. I felt better in myself and accepted the decision based on the fact that they were specialist doctors and knew best – chain of trust.

29. I went to my GP about the joint pain and he prescribed pain relief. I am sure the pain was exacerbated by the HCV infection. I have had haemophilia all my life and the pain from a sprain would last for a few days, but this went on for so long.

30. I did have a touch of depression for a short period after my HCV diagnosis. I worked in a big office at the time and in-between work on electronic documents I would go and sit in the back office when I was feeling a bit down. It felt as though

I was only gone for 5 minutes, but at times I would be gone for up to an hour. I was not sleeping at the time because of the worry and discomfort of my liver, but I did not want to take this back home to my wife and children. To confirm, I never asked for any medication from my GP to treat the depression.

31. I told my dentist about the infection and again this was off my own back. I was never given any advice from the hospital about risk or informing my dentist. I could not have any dental treatment without receiving Factor VIII or tranexamic acid to thicken my blood beforehand. The dentist would only see me during the last appointment of the day so that everything could be sterilised. I was treated like an outcast. I did inform them once my viral load for HCV was minimal, but they continued to treat me the same way.

32. I inherited varicose veins from my mother and as a result my legs have had to be stripped four times. I never experienced any difference in treatment because of my HCV infection in respect of the treatment for my varicose veins.

33. In May/June 2007, a vein popped in my leg and this resulted in a horrendous bleed at work. My colleagues were aware that I had haemophilia, but only my direct supervisor knew about my HCV infection (it later transpired that he did not relay this information to my other colleagues). He was an outside friend and I presume he did not want to tell the wider workforce because it was very personal – nevertheless this did not help me in this particular situation. There was blood everywhere and I had to drop to the floor and instruct a colleague to put gloves on and apply pressure to my leg. I told my co-workers to leave me alone and not to come into contact with my blood. It was horrendous there was blood everywhere even down the corridors. I was doing shift work at the time and the incident happened around 10pm at night. I came back home to strap my leg and to raise it, which stopped the bleeding.

34. The next day I received a phone call from the Steriles Manager to say that he wanted to come and visit me with the HR manager. They came around to my house and the meeting was very civil. They asked what strain of hepatitis I had, as those who had cleaned up my blood were sent to Worthing Hospital to be tested. I was happy to help, but my supervisor never stepped in to say that he was

previously made aware of my infection. I phoned the hospital whilst they were at my house so they could speak to the clinician direct. Five or six of my colleagues were sent to Worthing to be tested.

35. I could no longer work on shifts and in a sterile environment because I was a danger to the product and a danger to myself should anything happen again (as there were no cameras in that department and they said that if I was working alone and had a bleed it was too much of a risk). I lost over 40% of my wages overnight and I was very upset. It was confirmed when I returned to work that I would permanently be on day duty outside of the sterile area. It angered me that I had built up my career and held responsibility for training others, yet this was all lost suddenly. Others commented that I was still lucky to have my job, so I had to just bite my tongue and carry on. I continued to work days and I underwent an operation for my legs to be stripped in September 2007. It was a case of waiting, to be fair to GSK even they phoned to push the hospital because I was a risk and they were afraid in case I had another leg bleed. As a result, I had to remain in the office until I had my legs stripped.

36. I ended up working in data validation because I had so much knowledge of the plant. Despite this, I was treated differently to everyone else (like a second-class citizen) and I was made to feel that I was there purely because of my own fault. The irony was that all of the people in the office came to me for information and assistance. The odd snide comment would be made about me, such as don't upset him or he'll go running to HR.

37. Two days after the incident at work, I was out the front of my house waving my two sons off to school, when the wife of one of my colleagues (who I had never met before) came up to me and directly asked if I was Simon Payne. She went on to comment that I had put her husband's life at risk. I will never forget what she said and her comment was definitely the worst stigma I have experienced.

38. When I worked in the office environment I faced a lot of backlash and stigma because of my HCV infection. People avoided me as if I had the plague and I was treated like a second-rate citizen. At this point the penny dropped and I realised

the full implications of the infection, which I had contracted through no fault of my own.

39. The company provided 12 months of shift pay when I started working days as a transitional measure. My only other choice was to leave, so I took what they offered.

40. I was made redundant from GSK in October 2020 – this was not due to the pandemic, but due to the fact that operations have moved abroad. I did not realise the impact on my workplace pension from switching to days only. I am on £1000 less per month that I would have received, had I continued to do shift work. I am bitter about this, but I have no choice but to look for other work until I receive the state pension.

41. I started a new job at a speaker production company a couple of weeks ago, but I only lasted a day. I was not made aware that there were metal inserts inside the speakers and it was common for operatives to cut their thumbs and hands. I finished the training and they called me into the office. They were not willing to provide hand protection because of my haemophilia and we agreed that I could not continue with the work.

42. I never told anyone else about the infection because I was embarrassed. This statement interview is the first time I have openly spoken about the virus (other than to my immediate family and supervisor at work).

43. My wife is one in a million and very understanding of my haemophilia and HCV infection. After my decrease in salary, she went out and found work to make up the difference in household income. I feel as though I have let my family down, a feeling of just worthlessness.

44. I took out travel insurance to take my children to Florida in 2006 and I declared my HCV infection. I wanted to go regardless, so I paid the higher premium.

Section 6. Treatment/Care/Support

45. I have never been offered counselling or psychological support in relation to my HCV infection. However, very recently in March 2020 a haematologist from St Thomas' Hospital, Dr Bevan, whom I had not met, rang me about an appointment and asked if I had ever been offered any psychological counselling or support or if I had re-applied for any financial support as the Government position was changing. This seemed ironic to me, because for many years we were just left to get on with it and then all of a sudden someone I had never met, rang me up out of the blue asking if I had applied for this and that.

46. However, my GP Dr Sayers, has been brilliant and supportive throughout.

47. Without a doubt, I receive better treatment at St Thomas' Hospital than I did in Worthing and everything is checked thoroughly, but there is no continuity in haematologists and I see someone different for each appointment.

Section 7. Financial Assistance

48. In 2006/7 one of the haematologists at St Thomas' Hospital (a stocky Canadian guy) mentioned about the financial assistance provided by the Skipton Fund and he encouraged me to apply. I believe it was during our second appointment together. He said that he would get hold of the paperwork and fill out the application. Under Part 3 iii of the application form, the haematologist states that I was referred to St Thomas' Hospital on 31 July 2007 from Worthing Hospital and that I was treated there since 1977 with Factor VIII products. I exhibit the application form as **WITN5483002.** I would have been none the wiser had the haematologist not mentioned the Skipton Fund.

49. I completed the application form on 12 August 2007, but it was rejected on the basis that there was a lack of medical evidence. I have been shown the rejection letter from Skipton by the Investigator and I wish to exhibit this as **WITN5483003**. The letter states that in order to process the claim they require evidence to confirm that I was infected with HCV beyond the acute phase (beyond the first 6 months) and this could be evidenced by raised liver function tests. I did not clear the virus

within 6 months, but St Thomas' or Worthing Hospital did not provide documentation to prove this was the case.

50. I shredded the Skipton refusal letter a few months after I received it as I concluded that nothing would happen from it. I did not appeal the decision and left it in the hands of the Haematologist who initiated the application. I presumed he would have chased it up, but when I next saw him it was more the opposite and he did not want to pursue with an appeal. This was the last time I saw that particular Haematologist.

51. The Haematologist, Dr Bevan, who phoned in March 2020 regarding my liver scan recommended that I submit a new application for financial assistance, as mentioned earlier. My GP Dr Sayers, reiterated this during an appointment in September 2020 and commented that I have nothing to lose from reapplying. He went on to say that as a haemophiliac with HCV, contaminated blood is the source of my infection. He said, "You have got haemophilia and that is a fact, you got HCV and that is a fact, you've had contaminated Factor VIII, so you have nothing to lose." I have made the hospital appointment letter dated 5 February 2020, available to the Inquiry, which clearly states that I received contaminated blood. **WITN5483004**

Section 8. Other Issues

52. I have not been involved in any of the previous Inquiries.

53. I was first aware of the Infected Blood Inquiry when I saw it on the news last year. However, I started to look at the work of the Infected Blood Inquiry, after I was contacted by an Inquiry Investigator. I found a few of the witness statements online and immediately thought 'that's me'.

54. I had followed the news coverage of the Inquiry, but this should have happened years ago. So many people have died as a result of the contaminated blood scandal and in that respect, I guess I am one of the lucky ones. I could sit back and feel sorry for myself, but I just have to get on with life.

55. No amount of money will ever solve the problem – it is in effect blood money. I do not think people realise how much it affects you when you receive an infection through no fault of your own.

56. I did not want to bring my wife to the interview today because I did not want her to see me upset. I have never spoken to anyone else about it, not even my brothers. Giving my statement is the first time I have spoken about it to anyone else.

57. When I went for my COVID injection, I had to take tranexamic acid the night before to control the bleeding because it is an intramuscular injection. This is just run of the mill practice because of my haemophilia.

Statement of Truth

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

Signed GRO-C

Dated 30/03/2021

Exhibit Number	**Description**	**Date**
WITN5483002	Skipton Application Form – Reference has been made to Part 3 iii filled out by the Canadian haematologist at St Thomas' Hospital	12/08/2007
WITN5483003	Skipton Rejection Letter	14/09/2007
WITN5483004	Hospital Appointment Letter from St Thomas' Hospital – stating that I contracted hepatitis C through contaminated Factor concentrates.	05/02/2020