Witness Name: Sylvia Grainger
Statement No.: WIT5306001
Exhibits: **WITN5306002**
Dated: 16th August 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SYLVIA GRAINGER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 19 July 2021.

I, Sylvia Grainger, will say as follows: -

Section 1. Introduction

1. My name is Sylvia Grainger. My date of birth is GRO-C 1959, and my address is GRO-C Lancashire GRO-C

2. This statement relates to my late husband, David Heys. He was born on GRO-C 1952 and was diagnosed with severe Haemophilia when he was four years old. He contracted Hepatitis C ("HCV") from blood products and then subsequently, liver cancer. He passed away on 20 March 2005, with complications from an operation directly related to the liver cancer.

3. I remarried in 2008 and now live with my second husband Graham. I am retired, having been an accountant within the NHS for 35 years. I have

never had any children of my own, though I have grown up step children through Graham.

4. I intend to speak about my late husband, David's haemophilia, and subsequent infection with HCV, which led to his liver cancer. In particular, the nature of his illness, how the illness affected him, the treatment he received, and its impact on him and our lives together.

5. I am not and have never been legally represented, and I am happy for my name to appear publicly on my statement. I do not wish to be anonymous.

Section 2. How Affected

6. I met David at my first job at a local company in 1976. He was an accountant, and I had just started as an account's clerk. I was 18 at the time, and David was 25. After we started dating in 1977, David and I decided that it would be best for him to get a job at another firm. We lived together for a few years and bought our first house in Gisburn, near Lancashire, in 1984. We married in 1991 when I was 32.

7. I knew David suffered with haemophilia when we started dating because I had heard about it in the office. I had done an A level course in biology when I was 16 and from that I had at least some awareness of the condition.

8. Apart from his haemophilia, David was in good health. He was a hard worker and despite his condition, he rarely took time off. We got on very well, he was fun, and he encouraged me with my career and over the years, I progressed from accounts clerk to qualified accountant. We both had a good work ethic and always tried as hard as possible for David's condition not to affect our jobs, even when we had been up all night at the hospital.

9. It was only really after we began dating and I had met David's parents that I started to understand the reality of his haemophilia. David's condition was severe haemophilia A. He used to have bleeds in his joints, elbows and knees in particular. As a result, this effected his walking.

10. David's mother explained a lot to me about what had happened when he was a child. She told me that there was no history of haemophilia in the family, he had only one sibling, a sister and she was not a carrier. He was as far as anybody knew, the first in the family to be a haemophiliac.

11. Therefore, when David was a small child and prior to his diagnosis, the family had no idea why he was continuously falling and suffering from bruising. At one point, social workers got involved because they thought his mother might be beating him.

12. It wasn't until a nurse friend of David's mother suggested that he could have a bleeding disorder that they took him for testing. As a result, David was diagnosed with Severe Haemophilia A at four years old. From then on, David was under the care of Manchester Royal Infirmary (MRI).

13. In the early 1950s and 1960s, there were no Factor VIII or plasma derivatives, and care for children with haemophilia was not good. There were no children's wards, and David had to spend time on the adult male wards whenever he suffered from a bleed. I understood from him that he had some horrific times on those wards.

14. David's haemophilia was so severe, that on a number of occasions, he had the last rites read to him, because they thought he was going to die.

15. One such occasion was when he was about seven years old, he had a severe bleed in his bowel, which made him constipated, so he could not

use the toilet. It was so serious that the medics thought he was going to die. Luckily, he pulled through.

16. The medical professionals were really not set up for haemophilia and there was no way to help him out more when he bled into his joints. It was not until the late 1980s and 1990s when they started to include orthopaedic professionals in managing their conditions - limb joints etc, that the care for haemophiliacs improved.

17. We first became aware of HIV/AIDS through the media and then the regular newsletter we used to get from the Haemophilia Society. This was around 1984, when David was still receiving cryoprecipitate on-demand from MRI.

18. We were pretty concerned about the risk, but the hospital assured us that cryoprecipitates ('cryo') were safe. Nevertheless, they started testing David for HIV every three months for two years.

19. Sometime between late 1984 and early 1985, the hospital switched to Factor VIII treatments. We still had to go to the hospital when needed but it was a much faster process than previously. With the cryo, there was always a delay waiting for the product to thaw before it could be used and then the slower process of administration. Factor VIII was just a case of injecting and then going home. It made a massive difference in the middle of the night, when we had work in the morning which incidentally, we pretty much always managed to get to. It took another year or so before David could start administering Factor VIII at home.

20. The switch to home treatments made a massive impact on our quality of life. David only had to feel the onset of a bleed, which he was very good at recognising by then, before, he would treat himself. Therefore, the treatment was instantaneous and not after an hour or so drive and then getting to the treatment room etc.

21. David had ongoing problems with his knee joints, which meant that he ultimately had to have two knee surgeries. I shall jump ahead slightly; sometime before his second knee surgery, I think this was in the early 2000s, David was diagnosed with HCV. He subsequently received treatment for this on a 12-month course of Peginterferon and Ribavirin, which successfully cleared the virus.

22. In 2004, David was diagnosed with liver cancer which the doctors confirmed was directly linked to contracting HCV. He died on 20 March 2005, days after a tumour embolism procedure to kill the cancer had failed and led to multiple organ failure.

Section 3. Other Infections

23. I do not believe that David received any infection other than HCV due to being given infected blood products.

24. vCJD was prevalent around the mid-2000s, and we received what I believe to be a standard, generic warning letter in the post about this and the possibility that David could have contracted it through blood products if a single donor had been carrying the condition. There were no tests available at that time to establish if David did have vCJD so, just another thing to worry about.

Section 4. Consent

25. I do not believe that David was treated or tested without his knowledge or consent. I think he would have consented to any treatment because he trusted the doctors who had always cared for him, and if it was any treatment that promised to make his quality of life better, he would be up for it.

Section 5. Impact

26. I started looking after David almost right away from when we began dating. We were spending a lot of time together, and his father was getting older and required a lot of care, so I pretty much took over from his mother. I used to go with him to MRI, which was about an hour's drive away, whenever he suffered a bleed, which was, on average, once every three weeks at the time.

27. He would be given cryoprecipitate at the hospital, and he was on that for the first six or seven years of us being together, so well into the 1980s.

28. During this time, David had to have cryoprecipitate on demand. At times we could phone ahead, when he was suffering from a bleed so they could send for the cryo from the lab before we arrived at the hospital. However, on some occasions, they would wait for our arrival to assess him before they sent for the blood product. It would then need to thaw, which lengthened our stay at the hospital.

29. It meant that we could be at the hospital for hours, frequently well into the night or for hours during the day. The cryoprecipitate had the tendency to give David hives and occasionally breathing problems which would require the administration of an antihistamine like piriton so that he could settle. It meant that we spent long hours in the hospital.

30. It was only around late 1984 or early 1985 that the hospital switched to Factor VIII treatments. We had to wait another year or so before he could start administering Factor VIII at home. I remember this because we had been living in the cottage, we bought for at least a year before a nurse came around to inspect whether it would be a suitable environment to have home treatment.

31. Around 1985 or 1986, a nurse came around to train David and also me as backup, on how to administer the home treatment. First, they checked

whether we had a good fridge to store the products and whether it would be a nice, safe environment.

32. I don't know the reason why they made us carry on using cryoprecipitate rather than the factor VIII derivatives like most of the other haemophilia centres. We used to joke that MRI was the poor relation of the other haemophilia centres. At the time, I used to think it was because of the hospital's finances. I think that some of the consultants struggled against the people in charge to get funding. Although looking back, perhaps some doctors knew that there were risks to using the Factor derivatives. I have no way of knowing which was in fact the case.

33. I was 24 years old and working at Chorley hospital as an accountant when the news of AIDS broke across the country. I remember that they said that the virus was now affecting haemophiliacs. Previously it had been said to be predominantly affecting members of the gay community. David was still using cryoprecipitate at the time, but from then on started getting tested for AIDs every three months. We were not told the results, just by another invite for the next test, this continued for about 2 years.

34. When David was finally switched over to Factor VIII, it made a huge difference in our quality of life. Even before he began home treatment, it did not require thawing like cryoprecipitate, so we were able to spend less time at the hospital.

35. Travelling back and forth to MRI was exhausting, and we would always go to work the next day irrespective of how long we had spent at the hospital or how late we got back home. We never missed work, and we had a good work ethic. It didn't matter how tired we were. We did the best we could to work.

36. I remember one particularly bad phase when David had bitten into his tongue, it would not stop bleeding no matter how much cryo they gave him, finally they sent for a special topical application from the Liverpool

centre for tropical medicine which turned out to be snake venom, it did the trick.

37. David was having problems with his knees, and they gradually got worse over the years. One was worse than the other, but at one point, we were travelling up to MRI two or three times a week. There was a closer sub-centre at Blackburn Royal, but it was not a big one, and at the time, because of the severity of David's bleeds, I do not think they would have taken him on there. MRI had always been his hospital since he was a child under the care of initially, Dr Delamore.

38. By the time we started dating, his consultant was Dr Wendsley, although I never met him. He briefly had another doctor called Dr Lucas, but again, I never met him, and that did not last long. Later, and up until he passed away, his consultant at MRI was Dr Charles Hay, now a Professor. He became David's consultant from when he first started working at MRI, and I met him a few times.

39. I should point out that I rarely attended consultations with David but I would invariably be with him when he needed treatment for bleeds.

40. When we became aware of HIV, I remember speaking to David, asking if he was sure that this treatment was absolutely okay. When Dr Wendsley retired, and Dr Hay came on to the MRI team, he seemed to be more forward-thinking. He began to fight for more funding and for the switch to the use of Factor products.

41. Recently, I found out that Dr Wendsley preferred cryoprecipitate to Factor VIII. perhaps he might have had doubts about the products. It turned out that it worked out for many of the haemophiliacs there, because they escaped AIDS. I have no idea whether this was as a result of something the medics at MRI knew, or simply that they had been deprived of funding.

42. Prior to David being moved on to Factor VIII, we used to have to take details of the nearest haemophilia centres whenever we went on holiday because David was on cryoprecipitate. On one occasion, when we turned up at a centre near Newquay, they were shocked that he was still on cryoprecipitate.

43. I think we knew or found out at some point that the reason the people on cryoprecipitate were not getting AIDS was that there was an added element in the Factor products in comparison because of the way it was derived. We understood that the blood was sourced from Americans who had received payment for their blood donations, that it attracted people who needed money rather than doing it for altruistic reasons and therefore those whose lifestyle may have not been conducive to healthy blood supplies. Prisoners too, were donating.

44. I think it was in the Haemophilia Society's newsletter that nine out of ten patients at the Newcastle centre, which had all the haemophilia patients being treated with derived factor products, had contracted AIDS.

45. I was aware through working in the NHS for many years, that it needed around 8 pints of whole blood just to make a small amount of Factor VIII back then. Therefore, it could not satisfy the demand and be solely produced locally or UK wide.

46. For the most part, MRI were good at communicating with us openly, so when David went on the Factor VIII, we were able to voice our concerns about the risks and possibility of contracting AIDS.

47. David came home from one of his appointments with the consultants, the regular ones which I did not attend, to say that he had been assured that Factor products were heat treated. We were not aware of Hepatitis C at this stage.

48. When David started receiving Factor VIII, they carried on testing him for AIDS every three months, for two years before they stopped. Then they said there was no more need for tests and that it was no longer possible for him to contract AIDS. As usual, we accepted this.

49. We never had any issues with MRI, or their staff. We were confident that they would tell us if one of the results came back positive. I never went to the tests with David, so this was always relayed back to me. I always had faith in what he told me, although later on, I did find out there was some information that he hid to protect me, and I understood why with hindsight, he just may not have wanted to give me anything more to worry about. I know that he liked to keep the MRI side of things separate from our home life/relationship as much as he could.

50. From 1986 to 1988, we had started hearing about non-A non-B hepatitis. This was from the Haemophilia Society, but they said that it was nothing to worry about. That the infection could be in blood products, but it seemed not to be causing problems in terms of health issues. I am pretty sure we either had a letter or David was told that it was not a cause for concern from Manchester.

51. One of David's knee joints was getting so bad he would require knee replacement surgery, especially as knee replacements were very much routine and all the rage back then. Dr Hay was delaying and fighting against this, what we considered essential and very necessary procedure. I was sceptical about the reasons why. As an NHS accountant, I knew the cost of replacing a knee but also the amount of Factor VIII that would be needed for David to be operated upon. I may also be being unfair and maybe Dr Hay knew the risks to David from the increase in factor products that he would need.

52. It began to make us both quite ill. We were not sleeping because David was in so much pain at night and couldn't sleep, which was consequently

affecting my sleep. He was suffering from more bleeding and was taking Factor VIII every day at this stage.

53. I could not bear it. It's only now in my 60s and experiencing some arthritis that I can appreciate the extent of David's pain and just how horrendous it must have been for him.

54. This was after we had started getting home treatment and was a couple of years in the run-up to 1993/1994 when he finally had his first knee replacement surgery.

55. For the most part, the Factor VIII was a BPL product, I think at some point there may have been a break, and he had received another product, and much later, it was Recombinant Factor VIII.

56. Home treatment really changed our life. We were so thankful and blown away because he only had to feel a tiny heat in his joints, which was how he knew he had a bleed and he would take an injection which would ease things right away. It was great because it sorted the problem out very quickly, and we were able to get back to a relatively normal life.

57. By this stage, we were both senior accountants with thriving careers earning good salaries. The treatment made a massive difference to David's wellbeing and our life together.

58. He had always been prosaic about life and his haemophilia. He had made it clear with me from the start, that his life expectancy was not great because of his haemophilia. I remember when he was in his early 30s, he exclaimed, "They said he would never get past 30. So, this is really great".

59. Even with all the pain in his joints, he had a really good zest for life. By the age of 50, he had had two knee operations and was still full of life. Even after being diagnosed with HCV, he was so philosophical and

retained his positive outlook. I guess that he viewed that his life had been extended well beyond what he had imagined.

60. In the early days of our relationship, I did have tentative visions of a family, but the appearance of AIDS was one of the biggest factors in us deciding not to have children. It was very frightening, and it felt like AIDS was hovering over us. We were so worried that anything could happen, and David did not want to leave me a one-parent family under these circumstances. The added stigma attached to AIDS was horrible.

61. At the time, I was working at Chorley as a general accountant taking my professional exams and working with a team of people. I never hid the fact that David was a haemophiliac, so my colleagues were aware.

62. Consequently, when the news of AIDS broke, it was quite upsetting for me because on one occasion, one of my colleagues came to speak to me about some woman spreading information about "me and my partner's situation".

63. According to her, the woman had suggested that I should no longer be allowed to use the women's toilets at work because David was susceptible to contracting AIDS.

64. It was awful, but the rest of my team supported me, and we had to have a meeting with my supervisor, who was also very supportive, and that was the last I ever had to deal with it at work.

65. Due to the stigma attached and the worry when concerns started about hepatitis, David and I discussed getting vaccinated against hepatitis, and I decided to get vaccinated for Hepatitis B through occupational health at work.

66. By 1993 I was working at Burnley General Hospital. Therefore, when the pain in David's knee joint started affecting our sleep, and

consequently my work, the medical director at the hospital pulled me aside to ask if there was an issue because he could see that my work was suffering. I explained about David and his constant bleeds at the time, causing us both sleeplessness. He said that he knew some people in MRI, and within two weeks, David had a date for his operation.

67. The next time we saw Dr Hay, he joked to David that "your wife has some very influential friends". The surgery was a real turning point, and our quality of life improved dramatically after David had the knee operation.

68. He got a job as a Finance Director for a company based in Clitheroe with a sister company in North Carolina, US. He was able to fly out regularly to work in America with his boss. He would travel to America to work for two weeks every six weeks or so.

69. It was tiring due to the nature of the job and the constant jet lag but David was thrilled doing that for a while. He was a brilliant and determined man who never let the poor quality of education he must have had as a child with haemophilia, get in the way of his goals. I look back now with pride at how much he tried to prepare and keep us financially secure for the future.

70. David did not experience a lot of noticeable symptoms of HCV at first. He was always very tired, but I associated it with the stresses of life, how hard he was working, the regular jet lag and the bleeds in his second knee getting worse.

71. However, he started getting more and more tired and said that he could not keep up with the travelling and the bleed in his knee joints. He was taking more treatments and even tried Factor VIII as prophylaxis at some point but stopped that for some reason, possibly advice or perhaps it was part of a trial. I am not sure. Consequently, he stopped travelling to

America and stepped down into a more managerial role where he could do all the management director aspects while his boss did all the travel.

72. Again, with getting a second knee replacement surgery, we had to push the hospital to give him the operation. MRI had introduced a double clinic with orthopaedics and haematology at this point, and the orthopaedics team had to force haematology's hand into doing the surgery. The orthopaedic surgeon said, "if you don't agree to secure funding for this, he will lose his leg, not just the knee".

73. I always assumed that it was the cost of hospitalising David that caused the delay because, as a haemophiliac, it would cost thousands and thousands of pounds to ensure the safety of the operation. I can't say now if they were worried about the higher risk of him contracting an infection through the greater use of Factor VIII, in order to have the operation.

74. When they finally agreed to do the second surgery, David came home from one of his regular doctor's appointments at MRI to say that he had good news and bad news. He said that the good news was they were going to do the surgery, and the bad news was that he had tested positive for HCV.

75. He said that they told him it was really serious, but he had a 50% chance of clearing the virus, and he could begin treatment after he had recovered from his knee operation.

76. After the knee surgery, David contracted MRSA from the hospital. One day soon after, he had been at work when the stitches burst, and he had to be taken back to the hospital. He remained in the hospital for over a week while they tried to clear the infection. Every night they took him to the theatre as the last patient for a deep clean. They had to clean the entire theatre before they could bring him in. They did this for several nights, cleaning out the infection, and luckily it worked.

77. We were given a lot of information with regards to HCV. We had leaflets, and the haemophilia society magazine said that the risk of partner's contracting HCV was minimal, so I was not too worried about contracting it.

78. We had always been aware of the risk associated with the transference of blood and bodily fluids. First due to the nature of working in a hospital environment, and the big uproar when AIDS came up, and finally, right from when the nurse practitioner came to our house when we started home treatments, we knew we had to be careful about things like sharing toothbrushes, and towels. However, we had a discussion, and it did not affect the intimate relationship side of our life, because the quality of our life together was more important for us.

79. I was aware of things like needlestick injuries, we had a sharps bin and I even used my contacts at the hospital, instead of driving up to Manchester, we arranged for the home treatment items, i.e. Factor VIII, needles, syringes etc. to be delivered to our pathology lab at Burnley. So, I had an advantage that others did not with all the travelling, it was great for disposing of everything too.

80. I was also tested for HCV. Although David said that MRI had informed him that there was testing available for partners, I chose to do my test through my workplace hospital instead.

81. We were always social people, and David liked to hang out with his friends for the occasional beer, or wine, and a smoke. It was one of the simple pleasures for him, and he was not willing to give up the few things that made him happy.

82. After David's second knee surgery, we had a BBQ at home. One of David's friends, and his wife and two little daughters were there. I remember this friend was asking me about how David health was doing,

especially because of everything in the news about haemophiliacs, AIDS, and HCV.

83. I explained that he was doing well. He had just had knee surgery and was walking well, so not in pain, but unfortunately had been diagnosed with HCV. His friend agreed that David looked well but said he was worried about this HCV David had now contracted.

84. His wife overheard us talking and immediately recoiled. She stood up, grabbed the two girls close to her and exclaimed, "he's got hepatitis". I could not believe that she was being so melodramatic. She was a teacher, yet she was behaving like this.

85. The husband was one of David's best friends, so he was embarrassed by his wife's actions. David heard the commotion and went ballistic at me for telling anybody. He said it wasn't news he would tell a man on the street because they would not understand. "You can't tell just anybody that. The next news is we would be pariahs". I never told anybody about it after that. We saw his friend, but we never saw his wife or the children again. It was horrible.

86. Three months after his knee surgery, David began treatment for HCV. He was given Peginterferon and Ribavirin. Through my job, I knew what these were in terms of cost and that one of the drugs was under license for trial for the treatment of some cancers at our hospital. I knew some types of interferon were used in treatment of AIDS, so I realised that there could be some negative side effects.

87. I think that the consultants may have explained some of these negative side effects to David, but he did not pass them on to me at the time. It was only after some of these side effects began to manifest that I realised this.

88. The Peginterferons had to be administered subcutaneously into the stomach, while Ribavirin was taken in tablet form. I can't remember how often he took them, but he had to administer the injections himself at home. He made regular visits to the hospital for check-ups during this period.

89. He lost a lot of weight. He was pretty chunky before, so he did not look too skinny. He was very tired, more so than before. The worst side effects were irritability and anger. I didn't know where this came from, and I had never seen him behave in this manner before.

90. The change in his personality was almost psychotic. It built up, over the course of the treatment, and coalesced into sheer rage around four or five months into the treatment. It was a nightmare. It started with slight bits of anger, randomly flying off the handle at tiny stupid things.

91. I can remember one occasion when David he was on his way out, and I had hung a jacket of his on a metal hook hanger in the kitchen. When he reached for the jacket, the hanger snagged a small thread on the jacket's collar. He saw it and was incandescent with rage at this tiny thread being pulled. It was completely out of character. This was something else entirely.

92. David had been in pain before and had never reacted this way to things. I don't think he recognised it. If he did realise, he couldn't voice it to me. He withdrew completely into himself and shut me out completely. It was almost like he couldn't bear to be with me but maybe he was making sure that I was not exposed to it and/or it was his coping mechanism. It was an all-consuming anger.

93. I became depressed and tearful due to living with David's high emotions. He wasn't speaking to me about anything, and I was on edge. I thought he might want a divorce or something, that I was the problem. I didn't put it down to the medication until I went to see my GP because I thought I

might need some help. We had the same GP, and the doctor asked me if I thought this could be a result of the medication. After this, I asked some of the pathology technicians at work if the medications could be causing these fits of anger and withdrawal, and they explained that some of the people with AIDS were having trouble with it too.

94. While on the medication, he continued to work for the most part unless he was really struggling, then he would have the odd day off work. He changed his hours to something like 8-4 pm, which was shorter days for him, he used to work till 7pm. He may have informed his boss, but I don't think he would have let anyone else at his work know. He had shut me out completely, so all I really knew at the time was that he had check-ups and blood tests to see if he was clear.

95. Around six months into his treatment, I got some counselling through my GP instead of going on antidepressants. I later found out that that counselling could have been made available to me via the haemophilia centre, after David found out that I was having counselling.

96. Since he was doing shorter days, he got home before me one day, and a call came for me on the home phone from the counselling service. Strangely, as I don't think that should have happened, they informed him that I was receiving counselling, or it was obvious from what they had said. Either way, when I came home, David told me about the call and asked me why I had not told him that I was struggling. I explained that I did not want to tell him before because I didn't want to add to everything that was already on his plate.

97. He was very apologetic about his behaviour and the impact that it had on me. He said that he had known this may be a problem. He said that MRI had informed him that they could provide counselling services for both of us. He had not taken it up or told me. After that though, things got a lot better. I told him he couldn't keep it all in. He explained that he was still trying to get a handle on it himself and that this is how he fights

to stay alive, and that he had been doing it alone since he was a little boy. It cleared the air, and his anger seemed to abate thereafter.

98. After the planned six months of treatment, he went for liver function tests which showed that he had not cleared the HCV and would need to continue on the treatment for a further six months. This worked, and we were relieved that he had cleared the virus.

99. I never heard about the state of his liver, cirrhosis and the progression of that side of things. I know Dr Hay mentioned cirrhosis on one occasion because David came home and said, "Cirrhosis has been mentioned because I've been drinking wine, but I'm not an alcoholic, I'm working and I have a reasonably good time when I can". That was the only time I've ever heard cirrhosis being mentioned.

100. The only time he didn't drink was when he was on Ribavirin and Peginterferon, but as soon as he cleared it, David had gone back to having a drink with his friends. I had even joked that the reason he had lost so much weight when he was on the treatment was that he was not drinking beer or wine. Still, he was never an excessive drinker, it was always a social thing.

101. He continued to have 6 monthly appointments and liver function tests at MRI. In July 2004, after our summer holidays, he came home from one of those appointments and said that the test results had shown he had a high liver function count, which was a problem. He would need to go for a scan, and after that, the doctors would like to see both of us in the next few weeks. It seemed like it was a matter of urgency.

102. In early August, we went for the scan. I can't remember which kind it was, but I think it was a radiological scan of David's liver. We ended up waiting for the test for a while and had to ring the hospital three or four weeks later to find out what was happening.

103. One of the nurses explained that Dr Hay and the team had only just returned from the World Haemophilia Conference, somewhere abroad, while the junior medics had been left looking after things. I thought there was something wrong because we had had such a big delay, but they explained that the scan results had been sent in wrongly via regular internal post rather than urgently.

104. It would have been possible to type up the results and send them to us in an email, but eventually, we were asked to come in to find out. In the first place, Dr Hay wouldn't see us, which was strange. He had always seen us apart from when he was on holiday. However, suddenly we were seeing a new consultant called Dr Bolton-Mags.

105. They informed us that the scans showed there was some sort of tumour on David's liver that would require a biopsy. Dr Bolton-Mags explained that David would be referred to a hepatologist consultant because they thought it was liver cancer. They also mentioned that it was always a risk that David's HCV could turn into liver cancer within five years.

106. David replied straight away that he had been made aware of this risk, but I had the biggest shock because I had never known of this. He said he had thought it was best not to worry me because it may never have happened. This is when it really dawned on me that maybe he did not always tell me everything.

107. The hepatologist consultant we were referred to was Dr Rachel Harry. She stated that she was the liaison between the haematology and Medical Hepatology services. She said she had just started working with haemophilia centres because of the rise in the manifestation of liver problems in people with HCV.

108. They took a tissue sample because they were reluctant to do a biopsy due to David's haemophilia. They explained that a biopsy would be a very dangerous procedure.

109. In November 2004, they sent us to St James Hospital in Leeds for another scan. Being at St James was heart breaking because it made it starkly clear why we were there. It was an end of life situation. All the patients there looked very ill, yellow and many were in wheelchairs.

110. At the hospital, they told us that David was not suitable for a liver transplant. I don't know why. I don't know if they explained why, I just can't remember, I just know that they said he was not suitable.

111. That Christmas, we travelled to France for a bit of a holiday. GRO-C GRO-C, and that was difficult for me as well.

112. After Christmas, we went back to see Drs Harry and Bolton-Mags. We never saw Dr GRO-D again. It felt like he had washed his hands of David. The perception was as though David was dying, and so someone else was dealing with that. "I've done my bit, you are dying, and that's it", was how we felt.

113. In January 2005, the two doctors informed us that David would die and that his prospects were between six more months and a very optimistic two years. They said they could try to do a tumour embolism procedure, which the hepatologist explained was a procedure that would be done under radiological conditions.

114. They would inject a substance in the vein through his leg, which would block all the exit holes out of the liver. His liver would then be sealed off from all of the other organs so they could inject the chemotherapy directly into the liver, to kill off the cancerous cells.

115. Both consultants were clear that his illness was fatal and agreed that it was most likely a result of the HCV. They were hoping that it may extend his life for up to two years, which was the best case that what we had been told to expect - 6 months to 2 years. David being David, agreed that he would be happy to try this plan.

116. I never had any doubts that the liver cancer was a direct result of HCV. I know that David had been told to stop smoking and drinking, but neither were excessive and only detracted from his general health.

117. He went in for the tumour embolism treatment either on a Tuesday or Wednesday but never made it out of the hospital past the weekend. He passed away on 20 March 2005.

118. I think the tumour embolism procedure was set for the day after he was admitted into MRI so that they could stabilise his Factor VIII levels before the procedure. Within half a day after the procedure, he was not well. I went into work as normal on the day he had the procedure and went into the hospital to see him that evening. He did not look well, but I thought that this was because he had just come out of surgery.

119. The next evening, I returned after work. He was on morphine because he was in such a tremendous amount of pain. MRI did not seem to know what they were doing. The next day, I went in earlier, late afternoon, to see if I could try and catch a consultant. I was able to get a hold of the ward sister, and she informed me that David was having a few problems, but they were unsure of the cause. She said they would get the radiologist who was there during the procedure to have a look.

120. Dr Harry came in later that day and eventually spoke to me. She said David's kidneys were failing. "We think the product has not sealed the liver and has escaped into his bloodstream, but he should be fine because it should only kill cancer cells". She explained that they would

have to see what happens to his kidneys, carry out scans and blood tests, and would continue giving him morphine for his pain.

121. The next day was Friday, and I went to work as usual. On my way out, I grabbed my friend, an anaesthetist at Burnley General Hospital, to accompany me to MRI because I wanted her to look at David.

122. She ended up driving me to the hospital. On our arrival, we were shocked at the state of chaos in the hospital. The wards were dirty, and there were virtually no staff to be found on the ward. My friend had to re-site David's cannula, which was used for administering the fluids and medication into David's body. It had fallen out of his arm and had not been replaced, such was the lack of attention and care he was getting.

123. I was trying to get anybody to come and speak to us. David was floating in and out of consciousness. When he was conscious, he would say lucid things, even darkly joking, such as "I didn't think it would be my kidneys that killed me". He was on a very high dose of morphine, so he was also saying things like, 'there are so many flies here, there are so many flies". Of course, there were none.

124. My friend told me to stay with him that night; I think she thought he would not make it until morning. I think David knew too. None of the consultants ever came near him after that, only junior staff.

125. I had never seen him in so much pain and agony. He couldn't breathe. Nobody could give me information. They did not find a bed in the critical care ward until 11 o'clock at night. Meanwhile, they left him at the High Dependency Unit (HDU), struggling to breathe.

126. At the HDU, someone had him put on an oxygen mask. He had always hated those oxygen masks because he could not tolerate the discomfort against his face, so he was struggling with that. I kept lifting it off his face so he could actually get the benefit of the oxygen. Then, a

Senior House Officer (SHO), who was the more senior of the junior doctors back then, they are no longer called that, started screaming in my face because of this.

127. I told the Matron of the HDU about the SHO's behaviour, her response was, "this girl is not coping". Finally, they got a registrar to come and take a look at David. The Registrar said she would have to intubate David, which meant that she would put a tube in his throat and put him on a ventilator. She said it was likely he would not wake up from this. "You will have to say goodbye. I will give you a few minutes".

128. The Matron had taken details of my brother and his wife earlier, and they arrived just before David was intubated. David said, "why are they here" and I told him they were there to help me. He said, "okay,". I couldn't say goodbye to him, I said I won't leave you, I will be right here all the time, he nodded but we never spoke again.

129. He didn't wake up. They took him to critical care, and I stayed there all weekend. It was very quick. Eventually, I came to realise that it was a blessing for him. It would have been awful for him to survived that and then having to go through a long protracted cancer, with the same inevitable ending.

130. An inquest was held after David's passing. The pathologist gave his evidence, and I was allowed by the coroner to question him. The pathologist explained that the tumour embolism procedure had failed, and the product that was supposed to block the exits from the liver had not been blocked. The chemotherapy dissipated by the bloodstream to all of David's major organs, primarily the kidneys, then his heart and lungs.

131. According to the pathologist, what was unknown to the other doctors previously was that the cancer had spread to other areas all over his body, not just the liver. I asked how they could not have known this

before. He explained that the other cancerous cells had been microscopic, he had only seen it under his microscope during his post mortem examination, so there was no way they could have known this.

132. Even now, I still don't know if they could have known the cancer had spread. Nevertheless, I accepted what the coroner said at the time because I was satisfied by the explanation of why it had happened so quickly.

133. This meant that once the chemotherapy was injected, it killed all the cancer cells, and by the time so many had died, many of David's organ functions had been compromised.

134. The cause of death on David's death certificate was stated as (a) Multi-organ failure following tumour embolism and (b) disseminated hepatocellular carcinoma with a verdict of accidental death. See death certificate exhibited as **WITN5306002**.

135. After the inquest, I took out a complaint against the hospital, not for anything previous, not even for the HCV. It was all about that last bit of time David spent in the hospital. It was appalling treatment. There had been no consultants in the hospital or on the wards to see him. It was like the haemophilia centre people had washed their hands off him. Where was Dr GRO-D? I filed a separate complaint against them.

136. Dr GRO-D turned up with a hospital administrator speaking on his behalf, saying he would need to leave after 10 minutes. I confronted this immediately and told Dr GRO-D that he was going nowhere. Part of my courage and ability to stand up to senior medics came from a depth of knowledge from 30 years of working with consultants, medics. I know how they work. This coupled with the fact that I had two colleagues and friends with me. One was a consultant anaesthetist, and the other was the head of critical care, a nursing manager. They were all good friends

and colleagues with in depth knowledge of the profession. So, I knew I had plenty of back-up, and we knew what we were doing.

137. I got an apology from Dr GRO-D of some sort. He tried to bluster by saying he wasn't really David's consultant. Maybe because he did not want to have the responsibility of another of his haemophiliacs dying, this hearing was probably around four or five months after David's passing.

138. I received an absolute apology from Dr GRO-D who said she had only been in hospital for six months. She said she had not known, but she did know. She had just left it to SHO's and the Registrar. It was cowardly. She said that she had herself learned from this experience, she had now put things in place and that the team as a whole had changed their practice.

139. It was all administrative talk, paying lip service after the fact, the radiologist who was supposed to explain what was wrong never turned up, even at this point.

140. I knew I could take matters further if I wanted to. I decided that my mental and physical health would not benefit by doing anything further. I still also had loyalty to the NHS, my employer over many years, I was not looking for compensation. My friends encouraged me to pull back from it and start to heal.

Section 6. Treatment/Care/Support

141. I don't believe David had any difficulties or obstacles in obtaining treatment, care and support due to being infected with HCV. As I mentioned earlier, for the most part, MRI were pretty open and communicative with us even when we were aware that financial constraints delayed us getting some treatments on time. They did not hesitate to offer David the HCV treatment after his second knee surgery.

142. I have always believed that the team at MRI generally were good to us and at their job, aside from David's ultimate stay in the hospital.

143. David informed me that MRI had offered counselling and psychological services we could take up, but I was fine with the counselling service I had received via access through my GP.

144. David had no problems accessing dental treatment. He mostly only went to the dentist for regular examinations. For anything else that may cause bleeding, such as cleaning or tooth extraction, he would have needed to be treated at a specialist dental clinic because of haemophilia-related precautions that would need to be taken.

Section 7. Financial Assistance

145. I first found out about the Skipton Fund from Dr Hay at one of David's regular appointments after he was diagnosed with HCV. Dr Hay said the infection with HCV qualified us to apply for financial support set up by the government.

146. I did not think that we needed money because we were financially comfortable, unlike many others, but David thought it might help with our mortgage and support me financially if he died, or we could use it as a rainy-day fund. So, we decided to apply.

147. The Skipton Fund sent us a letter with the forms and a waiver attached. The letter explained that we would be receiving these payments, ex gratia, on the basis that they were not admitting any fault. We filled in the forms but debated about signing the waiver because, as accountants, we knew exactly what we were signing. It was a no-fault - no consequences waiver, and they explained that the offer would be withdrawn if we did not sign this.

148. We knew we would be signing away our rights to any further legal recourse. They also said we could seek legal advice or discuss it with David's medical staff. Neither of us imagined that it was because they knew that there was a problem with the blood product beforehand. We had no intentions of litigation anyway, so we signed the form and the waiver. Unfortunately, I have since discovered that the waiver we signed is not on his Skipton file.

149. We were granted the stage one payment of £20,000 not long after that.

150. A couple of months after he had been diagnosed with liver cancer, David sent an email to the Skipton Fund that he had now been diagnosed with liver cancer and he was eligible for second stage payment. As it happened, David died intestate, which is why I did not realise the Fund had paid the second stage payment of £25,000 not long after his death. The £25,000 landed in the account three days after he died. I had no idea about annual payments. I never knew there was anything else I could apply for.

151. I was financially secure. He had made sure I was before he died, so I didn't need the funds. I had been following this Inquiry since it started, but I was not planning to get involved because I felt there were people worse off than I had been.

152. Sometime last year, I went on the Inquiry's website to have a look, and I read a statement from Nick Fish in which he said categorically nobody had to sign any waivers. It was then I decided that I had to get involved.

153. I contacted the Haemophilia Society by email to see if there was a way to prove that, and someone explained that because Skipton had been disbanded, I should contact Russel Cooke Solicitors because they were in possession of all of the Skipton files. I sent in my details to this solicitors, along with David's death certificate and my marriage

certificate, which they required for identification. They sent me the files about three weeks later with everything they had on file from David's application to the Fund.

154. The file contained the application forms and one email to David dated 2011 from Nick Fish saying that they'd called him several times and would like to discuss a top-up after the government had made some more funds available to them. I think that they were supposed to distribute it to him or his estate if he had passed away. In any event, there was no evidence of the waiver we had signed. I am happy to supply what I have regarding David's Skipton Fund file to the Inquiry, if it is helpful. I am afraid that I did not bring it along when I was interviewed by the Inquiry investigator.

155. I have come forward partly because I am annoyed by some of the statements made in support of the Skipton Fund by their representatives, saying Nick Fish made every effort to contact people. I feel like this aspect was misrepresented. Just a letter and a phone call to previously held details and then give just up, is not enough in my opinion.

156. In the last few months, I have also been in contact with representatives from the England Infected Blood Support Scheme (EIBSS) since finding out there is some other financial support I could be entitled to.

157. First, I was informed that Russel Cooke Solicitors would have to send the files directly to EIBSS. Otherwise, there was nothing they could do. I said fine and was able to arrange that with the firm. I got an email back from an EIBSS assessor right away on the same day they received the files, who said I was entitled to the automatic top-up and death benefits allowance and funeral costs allowance.

158. However, the administrative process of dealing with EIBSS has been difficult, and it makes me worry about whether things have not changed

since the Skipton Fund was taken over. I get a different assessor every time I call to speak to someone, which makes things difficult. Once, someone called me Shirley and was confused about whether I was entitled to death benefits and funeral grants. They were asking me to provide further information in order to get some of these, like my marriage certificate to my second husband and a copy of the receipt for David's funeral invoice to prove I was the one that paid the invoice, which I had provided to them. Just last week, after I sent my marriage certificate, someone contacted me and said that they were still waiting for it.

159. This has meant a lot of back and forth with EIBSS assessors and explaining to the funeral directors why I needed the invoice in the first place. Luckily, they keep good records, and I am past the stage at which I am cautious over speaking about what happened to David.

160. To date, I have only received the £1800 contribution towards the cost of David's funeral, I have recently been informed by the EIBSS after much correspondence and battling that I will now be paid the £25k top up due to David from many years ago in mid-August this year.

161. There is one final issue with the death benefits allowance of £10,000 because my application was refused on the basis that David's death certificate does not state that he had HCV. Which it would not have because he had been cleared of HCV by the time he passed away, even though the medical professionals have said that the liver cancer was definitely as a result of the HCV.

162. They told me to take it to their appeals panel, and I have gone to Professor Hay to seek his assistance with providing a letter in support. Prof Hay very kindly wrote back to say he would be happy to write that letter in support and that he can confirm that David definitely died as a direct result of what the HCV had caused. The appeals panel has put

the application on hold until receipt of Professor Hay's letter. This was about three and half weeks ago.

163. As far as EIBSS, the administrative issues should be fixed. The application forms on the website just don't work as they should. You end up having to print it off and write it by hand. The combination of annoying technical glitches, minor administrative issues, and having to deal with a different person with each communication makes for a very poor experience.

164. It makes me think they still haven't got their act together, or learned any lessons from the fiasco of the Skipton Fund. It's unprofessional in the way they organise themselves. I do not think that the assessors have been given any relevant medical knowledge to enable them to do their job efficiently and sensitively.

Section 8. Other Issues

165. David didn't believe, and I still don't believe, that the local on the ground clinicians had any idea that the blood products were so lethal. This Inquiry may prove me wrong. From what I've read, it may seem that there were people in the central government's cabinet offices and in the department of health who probably did know the extent of how dirty, for want of a better word, these blood products were.

166. I have been truly shocked at reading some of the other infected and affected witness statements and the amount of their suffering, it inspired me to add my voice to theirs.

167. I really detest the lies being told about what happened with the Skipton Fund by those representing the Skipton Fund in the hearings.

Statement of Truth

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

Signed GRO-C

Dated 16th August 2021