Witness Name: Gary Kenneth Sheriff
Statement No.: WITN1014001
Exhibits: WITN1014002 – WITN1014005
Dated: 10th October 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GARY KENNETH SHERIFF

I, **Gary Kenneth Sheriff,** will say as follows: -

Section 1: Introduction

1. My name is Gary Kenneth Sheriff. My date of birth is GRO-C 1959. I reside at GRO-C Worcestershire GRO-C I had two sons, Dean and Matthew, with my late first wife, Pauline. I met Pauline at school and she was two years younger than me, but her brother was in my class. I was just leaving school when our relationship started.

2. I married my second wife, Kim, in 2014. We had already known each other for a long time before that. I am employed full-time as a Marketing and Sales Manager. Kim works part-time in a care home and we have lived in GRO-C for five years.

Section 2: How infected

Haemophilia

3. I have severe haemophilia B, which means I have factor IX deficiency. My factor IX clotting is 0%. I was diagnosed as a haemophiliac when I was a baby. My parents noticed that I was frequently bruising and took me to the GP. The

GP thought that I might have haemophilia and they sent me to Birmingham Children's Hospital ("BCH") to be formally diagnosed. I would estimate I was diagnosed between the age of three months and 12 months.

4. I consider the better qualities of my character, such as that I am empathetic and caring, are connected to having haemophilia. My haemophiliac friends are also the same.

5. There is no family history of haemophilia B and we could not find anybody with the condition before me. GRO-C also has severe haemophilia B and we understand the gene was passed down on my mother's side of the family.

6. Pauline and I were taking a big risk by having children. The consultant haematologist, Dr Jonathan Wilde, discussed the risk with us around the time I married Pauline and we were planning a family. It would have been around 1983. The consultant told me that if they were boys, they would not have haemophilia or if they were girls, they could carry haemophilia. He did not try to talk us out of having children but he made his views clear to us.

7. Pauline wanted children and I did not want to deny her that. I was never in any doubt that I also wanted children. Thankfully, neither of my sons have haemophilia. Our two sons are very healthy, have good educations and jobs, and I believe that is my legacy.

8. After we had had our two sons, in approximately 1994, I had a vasectomy to prevent me from having any further children. We did not want to risk it again, and I thought it was more appropriate that I had surgery rather than Pauline.

Impact of haemophilia

9. The bleeding into my knees as a result of severe haemophilia has meant that I have arthritic knee joints and at only 29 years old I needed my first knee replacement. This was in my right knee, and lasted 15 years which I have been

told by the doctors is about average. The right knee then had to be replaced again, and just afterwards my left knee also had to be replaced.

10. In 2012, I slipped, fell and damaged by right knee. I went to the surgeon, Mr Marcus Green, at the Royal Orthopaedic Hospital who undertook blood tests and carried out an "aspiration" of my knee. This involved drawing fluid off to have it tested. The surgeon told me I needed a second stage knee replacement, due to an infection in the joint. This involved removing the metal work in my knee, inserting a spacer containing antibiotics into the knee joint, and thereafter taking oral antibiotics for three months. Following three months of treatment, the surgeon undertook further blood tests to assess whether the infection had cleared. Once the infection had cleared, the metal work could be replaced.

11. In June 2018 I fainted and fractured my right femur. I had to have a trauma repair at the Queen Elizabeth Hospital ("QE") in Birmingham where they placed a metal plate across the fracture to my femur, and screwed in place. The metal work in my knee joint was quite high up because the screws could not go deep enough. Unfortunately, the plate failed and the Royal Orthopaedic Hospital ("ROH") performed further surgery and took all the metalwork out of the joint. They discovered an infection and had to do another second stage replacement, as described above. The alternative to all of these operations was an amputation and I did not want to consider that.

12. The leg surgery has gone well and I do not need a crutch at home. I have been told that this replacement should last for the rest of my life. It has been 18 years since my last left knee replacement, and I am trying to ensure it lasts as long as possible.

13. Despite the issues I have experienced with my knee joints, I have tried to live a normal life and I have always worked full-time. However, the normal daily activities associated with going to work and leading a normal life, for example, climbing the stairs, have had an impact on my joints.

Treatment with blood products

14. From the time when I was first diagnosed until I was 12 years old, I was treated with Cryoprecipitate or plasma. To receive treatment, I would have to go to BCH and the admission could range from a few days to a few weeks.

15. On one occasion, when I was 12 years old, I was being treated with Cryoprecipitate and I went into mild anaphylactic shock. I was struggling to breathe and my skin became blotchy. The plan following this incident was to give me as little Cryoprecipitate as possible. If I did need treatment, they would give me medication to counteract the anaphylactic shock, like an antihistamine, which would lessen the symptoms.

16. When Factor IX blood product became available, I began treatment with that. I was first given Factor IX when my care was transferred from BCH to the QE. At BCH I had only ever been treated with Cryoprecipitate. The same consultant haematologist worked at both the QE and BCH. I was told to move my treatment to improve efficiencies at both hospitals.

17. I was treated with FIX BPL Factor IX blood products from 1978 to 1993 [exhibit WITN1014002]. Initially they did not provide me with Factor IX product as home treatment and so I had to be treated at the QE. I did not have any side effects with the treatment.

18. I cannot recall exactly when I moved to home treatment but it was around the same time as I married Pauline, in 1982. I recall keeping the Factor IX bottles at home after we were married. By way of training the haematology nurse monitored me administering it in the QE first. I knew what to do having seen the treatment being administered all my life and I did not have a fear of needles.

19. Our sons were born and home treatment continued. My bleeds were better controlled and they were not as severe. I believed home treatment was fantastic, as my haemophilia became manageable as a result.

20. After treatment with FIX BLP Factor IX product, I moved onto Alphanine and Replenine (BPL) between 1994 and 1998. I then moved to a mix of Octa FIX, Alphanine and FVII Baxter from 1998 until 2013.

21. Since then, whenever I have had surgery or dental extractions, I have been given Benefix. This is a short-acting blood product. I also have Alprolix once a week, which is a long acting, prophylactic, synthetic blood product. I have been having Alprolix for approximately a year and a half and I have not had any bleeds since.

22. It was a long time before Alprolix was made available to me. I was told by the QE that this was because availability of Alprolix treatment was based on your age and the number of years you had left at work. I understand that they treated the oldest and youngest severe haemophiliacs first, because it was still classed as a trial drug. It is still only selectively available now, due to cost.

23. I have been on home treatment ever since being trained to administer it at the age of 14, and I have coped well, although sometimes my veins are not very good. I have only had one side effect of Factor IX treatment, which was a sharp tingling across my forehead in around 2005. I spoke with the consultant haematologist, Dr Wilde, and he suggested putting it into my veins more slowly, which reduced that side effect. Prior to that I would try to treat myself as quickly as possible.

Diagnosis with Hepatitis C

24. I was surprised to be diagnosed with Hepatitis C in 1996, as I had not been experiencing any symptoms. I was given the diagnosis during a routine clinic appointment and I found it quite a difficult way to be told. It was almost as I was leaving the appointment that Dr Wilde mentioned that I had been exposed to Hepatitis C, and that I had tested positive for the virus.

25. Once I realised what he had said, I sat down again and I asked him to explain it to me. Dr Wilde tried to make the conversation positive and explained that treatment was available. I have never been told which batch of Factor IX infected me. I was just told that I had contracted Hepatitis C from contaminated blood products. I was told that I had three options: to undergo a liver biopsy; to do nothing; or to begin treatment. I was not given any information about Hepatitis C prognosis or transmission. I was only told about the options that were available to me. I chose to begin the treatment, which at the time was Interferon and Ribavirin. It was the worst time of my life.

26. I believe there has been a lasting impact on me because of the way the diagnosis was delivered. I do not think it should have been left until right at the end of the appointment and the news given to me as if it were an afterthought. I had friends and family who had also been infected and so I knew the significant impact of the diagnosis. I have also since found out that the Hepatitis C test had been carried out in 1992 and so there was a four-year delay in being informed of the diagnosis [exhibit WITN1014003].

Treatment for Hepatitis C

27. Dr Wilde referred me to the liver department at the QE. The liver specialist explained to me that a liver biopsy would tell me whether I had liver damage at that time or not. I felt it was irrelevant to know whether I had liver damage because I had the virus anyway. The liver specialist gave me more information about available treatment at that time and reiterated my three options. The specialist told me that if I did nothing, it was fairly likely that I would die.

28. After the first consultation with Dr Wilde, I spoke to Pauline about our options, and we decided together that I should have the treatment. The conversation with the liver specialist confirmed my decision. It was made clear to me that it was not a pleasant treatment and that in many ways it was described like treatment for cancer.

29. The treatment was to last 12 months and involved a subcutaneous injection and daily tablets at home. I commenced treatment in 1998. The further I got into the treatment, the worse the side effects seemed to be, but I focused on my goal which was to clear the virus. I experienced severe tiredness and weight loss on the treatment. Every month I would go to hospital to have the viral load checked and I saw that it started going down. I discuss the impact of the treatment on me and my family further in **section 5.**

30. After the 12 months of treatment I had a blood test to confirm whether I still had Hepatitis C. I was told that I had cleared the Hepatitis C virus in March 1999, before my divorce to Pauline was finalised, which I refer to further below. The virus cleared as a result of the combined treatment.

31. Following this initial test, I was then tested every six months for a period of three to four years. The tests were always negative for the Hepatitis C virus and so the tests moved to once per year for another three to four years. They probably still test my blood periodically now, but they do not tell me about it.

Section 3: Other Infections

32. The records provided to me by the UKHCDO suggest that I had a test for HIV in 1988 [exhibit WITN1014004]. The test was undertaken on a blood sample from 1 October 1985. I was not aware of this in 1988.

33. I received a letter from Dr Wilde in the haematology department at the QE in 2002, which explained I had been exposed to vCJD. I spoke to the QE on the telephone about the letter and the prognosis. I have seen in the records provided to me by the UKHCDO that I was exposed to vCJD in March 1989 and June 1997 [exhibited WITN1014005].

34. They told me vCJD could trigger one day and they gave me the symptoms to look out for, such as headaches. I have not had any symptoms yet. I was advised that there was nothing medically they could do to assist. I understand

there is unlikely to be any treatment for this infection, as there is not much research funding for it.

35. I decided to put vCJD to the back of my mind. Occasionally I receive a letter from the QE about vCJD and, because I am trying to forget about it, I have asked them to stop sending letters to me that refer to it. The letters keep reminding me about it and there is nothing I can do about it.

36. I did tell my family that I had been exposed to vCJD. They were concerned about the effect of it on me, as they saw the effect that Hepatitis C had on me. I do not view vCJD in the same way as Hepatitis C, as it cannot be treated. My view is that there is little point in letting the prospect of vCJD ruin my life. It does mean that I worry when I have a headache, particularly if it does not go away with painkillers, and I cannot entirely pretend that it is not there. I was not offered any counselling in respect of being exposed to vCJD.

37. I am not aware that I contracted any other infections from receiving contaminated blood products but it would not surprise me if I found out I had.

Section 4: Consent

38. At the time when I was first diagnosed with Hepatitis C, I was unaware that I had been tested for this infection. As I have set out above, the diagnosis came as a shock, and I was only told about it at the end of a routine appointment.

39. Since 2002 I have not had any recurrences of Hepatitis C; I have remained clear of the virus. Although I am not aware of it, I think they may be testing my blood periodically to confirm whether there has been a recurrence, but I do not think this is being done surreptitiously.

Section 5: Impact

Impact on education

40. When I was a child, I learned when a bleed was starting and I knew I would need to go into hospital. I left it to the last possible moment and waited until I was in a lot of pain before I would go to hospital. Otherwise I had a normal childhood, even playing rugby and football.

41. My education was affected by haemophilia as I struggled to keep up with the rest of the class because I had to have so much time school off during my primary school years. I was in a special school until secondary school, when I attended Cockshut Hill in Sheldon. I felt like a normal child when I left the special school. When I first went there, the children were made aware they had to be careful around me and if they saw me hurt myself, they had to report it to a teacher.

42. Secondary school was challenging for me. I did not want to go back to the special school and so I wanted to be able to manage it. I do not think the teachers treated me differently but they knew how to handle my haemophilia, and did not let things get out of hand, for example when in the playground.

43. I was bullied whilst at school, particularly due to my knee problems, as I was in callipers from the age of eight years old to around 13 years old. After that I had surgery to try to ease the problem. I did not experience any physical bullying at school. I became friendly with some of the tougher children and I felt they protected me.

Impact on marriage

44. The biggest impact of the treatment was on my relationship with Pauline. She did not cope very well with me undergoing treatment for Hepatitis C and she could not manage with the side effects. I had told her about the Hepatitis C diagnosis and we decided together that I should undergo the treatment. The reality was I could just about manage to go to work, but then every evening I would need to go straight to bed, to reserve energy for the next day. During

the weekends I also needed to rest, trying to gain strength for the following week at work. This inability to function day to day as a result of the treatment, led to marital problems.

45. Ultimately the treatment cost me my first marriage. Apart from the haemophilia and until I was diagnosed with Hepatitis C, I had led a normal life. But the impact of the treatment seemed to be that, to Pauline, I had become a disabled person, and it started affecting our marriage. Our relationship deteriorated and eventually fizzled out.

46. We got divorced in late 1999, following completion of my treatment. Following our divorce, Pauline sadly died from cancer.

Impact on me

47. During the treatment I went to counselling, which helped with the psychological impact of treatment. I discuss this further below in **section 6**. I still suffer from the ongoing side effects of Hepatitis C and the treatment to clear the virus. I suffer from brain fog and I am easily distracted. The brain fog started during the treatment for Hepatitis C and I am told it will continue. It does not affect my ability to make long-term decisions but it affects day-to-day functioning. It is like I get a lag in the brain sometimes.

48. My levels of concentration are not what they were before I was diagnosed and underwent treatment. My sons, and both Pauline and Kim, noticed that. I have to really concentrate, particularly at work. I have learned to cope with it better over the years. Sometimes I get angry and frustrated about it because I feel I am letting myself down.

Impact on family

49. At the point of my diagnosis, Pauline and I had already had our two boys and so there was a possibility that they were infected. I had asked the consultant haematologist whether the infection could have been passed to my sons and he said he could not give me a definitive yes or no answer to that question. He described it as Russian roulette. We made a decision that the children were

happy and therefore we would not have them tested. We did not want to put them through emotional trauma, which was potentially for no reason. We were comfortable with our decision not have our sons tested.

50. My sons are now 32 and 29 years old and they are both still alive and very healthy. They both know that I had Hepatitis C and they know if they wanted to be tested now, as adults, they could be. They both decided they do not want to be tested for Hepatitis C.

51. My sons saw what was happening to me throughout the treatment. My eldest son, Dean, said "*the treatment put a rock between you and my mother*". He was older than Matthew so he was more aware of the side effects and impact of the treatment.

52. The treatment also affected my relationship with my sons, as I was undergoing treatment during their formative years. At the time, they were around three and five years old. I could not be a real dad to them, for example I tried to kick a ball around with them, but I just had no energy.

53. At the time of my diagnosis with Hepatitis C and treatment in 1996, my mother was very ill. She did know about the Hepatitis C but I did not talk to her about it as I did not feel it was appropriate. My father was also aware of it but would not acknowledge it. I did try to explain it to him but it was my mother that understood it and the impact of it.

54. **GRO-C** also contracted Hepatitis C from contaminated blood products and I believe it made us closer. She went through Interferon and Ribavirin treatment at the same time as me. After we were diagnosed we sat and talked, just the two of us, because it is personal to us and we understood the impact of the virus. **GRO-C** was also diagnosed with Hepatitis C, but fortunately he was able to clear the virus naturally.

Impact on work

55. At 16 years old I left school and got a job as a Trainee Computer Operator. I was the office junior and it gave me a good overview of office work. I worked at the company for five years and became a Computer Operator. However, I did not find the job sufficiently challenging and I was also working night shifts, which was not as social as I wanted. I migrated naturally to a more social and challenging job working in sales. I became a sales person in pensions at 21 years old in around 1981, just before I got married for the first time.

56. Sales suited me as I am good at negotiating and I know how to interact with people, even though I am not highly educated; my GCSE grades were not good. I feel that haemophilia has defined me as a person, because it has made me a problem-solver. I am also respectful of other people's issues and sensitivities. It annoys me to see people being treated differently.

57. I believe my health has held me back in my career. I cannot do some of the activities that my colleagues can, such as playing golf and skiing. Since receiving treatment for Hepatitis C, I am unable to focus, which at work is difficult, as I work in a high-pressured and competitive industry. I believe the inability to concentrate has impacted on the progression of my career. I also find dealing with stress, even minor stressful situations, and coping with anxiety very difficult since the treatment. However, my employer would not admit my health has had an impact on progression and it is difficult to prove.

58. My employer has accepted that, as a result of my knee joint replacements over the last five years, I have had to have time off work. I often have to work at home instead of going into the office. However, I have not had any pressure from my employer to change this.

59. During my treatment for Hepatitis C, colleagues would say that they had noticed I was always tired and asked me why this was. I did not feel it was

necessary to explain. I did not feel that my employer at the time was particularly sympathetic, and I did not believe they could do anything to help with it anyway.

Impact on finances

60. I do not have any life insurance because it would be too expensive in light of my haemophilia and past Hepatitis C diagnosis.

61. Travel insurance is also expensive and I do have to contact numerous providers to ensure that I attain the best price. I have not specifically looked into the impact of liver disease due to Hepatitis C on my insurance. The Haemophilia Society recommends good brokers for insurance, which is helpful. It is one of the good things about The Haemophilia Society, as it gives haemophiliacs the opportunity to get the best deals on insurance possible. I enjoy travelling but to do so I need to be covered for any treatment relating to my haemophilia, Hepatitis C and knees, which could be costly abroad. I would estimate that I pay around £50-70 more per year for travel insurance than the average person.

62. I do not have the pension fund I would like to have before my retirement. During my working life there have been times where I could not afford to put more money into my pension fund as I could not sacrifice any more of my disposable income. I also felt that I could not guarantee that I would still be alive to take out my pension. For this reason, I also took out additional insurance from work to ensure Kim is able to manage financially if I died.

63. I am now 60 years old and had been contemplating early retirement due to problems with my physical and mental health. Unfortunately, I have found that I cannot afford to retire, as I do not have a sufficient pension fund to support me. I would really struggle financially and I would be a burden on my family and society. This would lead to greater anxieties and stress for me and I do not think I would be able to cope with being very dependent on my family.

64. I receive a Motability allowance for my car, but as I have always worked, I do not receive any other state benefits.

Stigma

65. I did have a few incidents where I experienced stigma at work. At the time of the first incident, I was using a crutch and it was obvious something was wrong with my legs. I had to explain that if people asked questions, which was difficult.

66. I did not tell my employer at that time, outright, that I had haemophilia but I told them that they could look through my medical records and I could explain anything they needed to understand. I felt it was important to give them this opportunity, because I was going to be driving a company vehicle and travelling for work. My employer did not overreact and they said they did not want to read my medical notes. I have noticed some colleagues' reaction to haemophilia as being overcautious.

67. Apart from my immediate family, nobody else is aware that I contracted and cleared the Hepatitis C virus. I felt that people thought of Hepatitis C in the same way as HIV, which was portrayed negatively. There was lots of scaremongering and falsehoods in the press.

68. I continued to work full-time during my treatment for Hepatitis C as I did not want to tell my employer about my diagnosis. This was because I felt there was a stigma associated with it.

Section 6: Treatment, Care and Support

Treatment

69. On one occasion, when I was an inpatient at the ROH, the staff were aware that I had been diagnosed with Hepatitis C and they were very curious as to how I had contracted it. They asked lots of questions, partly down to their ignorance. I did consider the questions were inappropriate to ask a patient directly.

Obstacles to and difficulties with treatment

70. When I was diagnosed with Hepatitis C, it was clearly stamped across my medical records. The label said "Hepatitis C infected" in red letters and it was a big red flag to anybody that was treating me. It felt quite blatant but then I understand if a doctor or nurse is treating me for the first time, then they need to know relevant concerns quickly. I was able to rationalise it. Sometimes it did feel like there was a flag above my head.

71. The worst treatment I received following my Hepatitis C diagnosis was from the dental hospital at the QE. I went to a dental appointment in around 1999 and the dentist walked in wearing rubber gloves, rubber boots, a hood and a face mask. I believe this was because I had been diagnosed with Hepatitis C.

72. The dentist was very inconsiderate and told me I was costing the NHS a fortune. I told him that if I could go to a regular dentist, rather than the dental hospital, then I would, but I am unable to because I have severe haemophilia. The dentist did not say anything after I gave this explanation and he continued my dental treatment.

73. Following the appointment, I told the consultant haematologist at the QE about the incident and he spoke with the dental hospital. I received a letter from the QE responding to my complaint. The letter confirmed it was a trainee dentist and he was acting on the advice he was given in relation to treating patients with Hepatitis C, in order to keep other patients safe. I accepted their response to the complaint because I did not want the hassle of taking it any further, but I do not think their response was good enough

74. At some point after my Hepatitis C diagnosis, I was also told by Dr Wilde that if I needed surgery, then I would have to persuade a doctor to do it, as he would have to dispose of all of the expensive equipment after the surgery.

Counselling

75. I was referred by the liver department at the QE to a counsellor, Bobby Reid, to help me through the Hepatitis C treatment. The counselling was available on the NHS. I decided to go to counselling and it helped me to rationalise the treatment and what was happening, in particular because I was having difficulties trying to be a father to my two sons during treatment and my relationship with Pauline was breaking down. At times, during my treatment, I was depressed and contemplated suicide. Counselling helped me to understand that I may not be able to be who I wanted to be, because of my health.

76. I had around 16 sessions of counselling over a three or four-month period. I recall going to counselling every Friday and I decided to stop counselling after three or four months, as I felt I was in a better place psychologically. The counsellor did tell me the sessions could continue if I wanted them to, but I felt I was able to cope without the counselling. By this point I was around two-thirds of the way through the Hepatitis C treatment.

77. At the same time, counselling was also offered to Pauline but she refused it because she saw it as marriage counselling. Unfortunately, most of the discussions I had with the counsellor were about Pauline and the breakdown of our marriage. Pauline did not want anything to do with the treatment or the counselling offered. I found it disappointing and it affected me a lot; my treatment had got us to this stage in our marriage.

78. I have also had counselling more recently for depression, as I had been contemplating suicide again. I attended cognitive behavioural therapy to help with this.

Section 7: Financial assistance

79. I received a one-off ex-gratia payment of £20,000 from the Skipton Fund in 1999. The application for the Skipton Fund required a lot of accompanying

medical evidence. However, once the application had been submitted, it was quite straightforward. It took around three months for the Skipton Fund to confirm I was eligible and for the payment to be made.

80. Approximately two years ago, the Caxton Fund funded six sessions of my CNT counselling and contributed to the cost to have my bathroom changed to a walk in shower room.

81. I now receive regular payments from EIBSS, which has recently significantly increased. I receive £2,223 a month. The increase came as a surprise. I am a little cynical about the increase in payment, as it has only happened as a result of the Inquiry and the recent publicity the contaminated blood scandal had received. I believe it was an attempt to calm unrest amongst the groups of infected and affected people.

82. Nevertheless, it is a significant amount of money to receive from EIBSS per month and it has enabled me to pay my mortgage off more quickly; I should be able to pay the mortgage off fully this year which takes away some of the financial burden.

Section 8: Other

83. I go to meetings with other haemophiliacs, where we talk about Hepatitis C and the progress of the Inquiry. I consider that haemophiliacs can be categorised into three types. Some want justice from the Inquiry; some want to find out what happened; and some want compensation. I do not fit into any of those categories and I believe *"whatever happens, happens".* It would be beneficial if those infected through contaminated blood products were properly compensated for it. It would mean I could think about retiring, but it would depend on the nature of the compensation and whether there were ongoing payments. At the moment, the payments I receive from the EIBSS help, but the letter from EIBSS states that the payments are reviewable, and so I do not know how long they will continue.

84. I believe there is a huge range of people with different experiences that the Inquiry needs to hear from. I believe I am one of the lucky ones; I contracted Hepatitis C and not HIV, and my infection was treated and has cleared. This Inquiry has allowed me to consider the significant impact that the contaminated blood scandal has had on people, as I have been able to read other people's accounts. For me, there has been an emotional, work-related and family-related impact, rather than a physical impact. There are people in much worse situations than me. However, I believe I have a very good account to provide to the Inquiry and the Inquiry needs to hear from a wide range of people.

Statement of Truth

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

Signed ..GRO-C...........................

Dated..10TH OCT 2019.......................