

Witness Name: Marilyn Park

Statement No: WITN5350001

Exhibits: **WITN5350002-0012**

Dated: **04-11-21**

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MARILYN JEAN PARK

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 16 April 2021.

I, Marilyn Park, will say as follows: -

Section 1. Introduction

1. My name is Marilyn Jean Park (nee Roope). My date of birth is [GRO-C] 1950. I live in [GRO-C], Middlesex and my full address is known to the Inquiry.
2. I am a retired Research Psychologist. I live with my husband, Stephen Park, we have been married for forty-eight years and we have no children. I am a carrier of Haemophilia - my clotting factor is between forty-seven per cent and fifty-seven per cent.
3. I intend to speak about my late father Eric Sidney Roope. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him, my family and our lives together.
4. I can confirm that I do not have legal representation and I am happy for the Inquiry Team to assist with my witness statement.

5. I do not wish to be anonymous, and I would not object to providing oral evidence, however it is not something that I would push to do.
6. The Inquiry Investigator has explained the anonymity and statement of approach procedure, and if I am to criticise a clinician or organisation, that they will have a right to respond to that criticism.
7. I wish to acknowledge that, as time passes, memories fade and so I have provided this witness statement to the Inquiry to the best of my knowledge. Having now accessed my father's medical records, the family are pleased to note that many of our pertinent recollections are confirmed.

Section 2. How Affected

8. My father was born on GRO-C 1920 and the date of his death was 25 September 2000. My father was a Motor Mechanic and had a passion for cars. My father was a sufferer of Haemophilia. He was infected with Hepatitis B (HBV) and Hepatitis C (HCV) as a result of contaminated blood products.
9. My father's whole life was punctuated by full stops caused by episodes of bleeding, for example, he was invalided out of the Royal Marines after suffering an injury in 1940 that necessitated him spending eighteen months in a Military Hospital. However, knowledge was very limited at that time and haemophilia was not formally diagnosed until many years later.
10. In 1964, a serious haemorrhage caused him to require thirty-two pints of blood before he could be stabilised. This occurred at Chase Farm Hospital in Enfield, where an Inquiry was later launched as to why that volume of blood had been required. We were told that doctors had literally queued up to donate their own blood, given the quantities required.
11. Following the hospital Inquiry there was a hiatus before my father was eventually referred to The Royal Free Hospital and was registered under the

care of Dr Katherine Dormandy in 1971. On 11 February 1971, my father was diagnosed with Haemophilia A with a clotting factor of three per cent. His haemophilia severity was categorised variously as mild, moderate, and severe throughout the years. His NHS number was CGD512740. His Royal Free Hospital number was 110958. The hiatus of seven years between this major haemorrhage and the diagnosis of Haemophilia was, we believe, in part due to incorrect interpretation of his test results. Following his haemorrhage my father had received several complete changes of blood and we believe that this confounded his subsequent testing and led to erroneous results.

12. The following doctors were key players in my father's haemophilia care. Dr Katherine M Dormandy, Professor Christine Lee, Dr Elenor Goldman and Dr P Kernoff. Dr Domandy was his initial doctor; she set up a first-class haemophilia department but died in 1978. Dr Elenor Goldman, and later Professor Christine Lee saw my father regularly during his haemophilia appointments. My husband, who went to most of my father's appointments with him, found them both to be very pleasant to my father. The family never met Dr Kernoff.
13. My father admired all of the doctors at the haemophilia centre. I have a longer list of doctors whom were involved in his later gallbladder surgery, which I can supply, if needed. Also, my husband recalls that my father always attended an annual review in the haemophilia department.
14. My father's small amount of natural clotting factor, later quantified as 3%, leant a tiny benefit which allowed him to have periods of near normality. However, he was always aware that his health status was tenuous and, even before his formal diagnosis, he had decided to pursue his trade (motor mechanic) as a sole trader, realising that his reliability as an employee could very easily be rendered questionable. Normality for my father still meant a very close relationship with The Royal Free Hospital. He still required frequent interventions, for example, prior to dental treatment, when a head cold caused days of nosebleeds, or when a bad cough caused internal bleeding around the rib cage. My father came to rely upon The Royal Free team, and had

nothing but praise for them. He trusted them completely. I would almost like to underline that. He had total faith and really relied on them.

15. My husband and I had always leant a significant level of support to both of my parents, and my husband, Stephen, nearly always accompanied my father to his Royal Free Hospital appointments, driving him from East Barnet to Hampstead. We were a very close family.

16. In 1976, my father suffered bouts of severe pain. Gallstones were diagnosed and a planned surgery to remove the gallbladder was arranged for early 1977. The Royal Free Hospital were intending to trial a 'laser knife' borrowed from Israel, and my father was told it would be used for his surgery. The procedure was to be filmed. It was quite a 'thing' in the hospital. It was a very expensive piece of equipment. My father's and one other surgery were being performed using the equipment. On the ward, everyone knew what was happening and the whole ward was buzzing.

17. The laser knife was being flown in for just one day from Israel. Through my personal speculation, the fact, it was for one day only, we now wonder whether the wish to ensure a trouble-free filming of the trial influenced the decision to include, at a late stage, the use of Factor VIII concentrate, in conjunction with cryoprecipitate. Records show that, in the course of this surgery my father was administered Factor VIII concentrate for the very first time. Please see **Exhibit WITN5350002**. This decision was not discussed with my father nor with the family.

18. The surgery was performed on 17 January 1977 by Dr Lewis and assisted by Professor Kaplan, using the laser knife equipment. I make **Exhibit WITN5350003** available to the Inquiry which references to its use.

19. We were told that the film footage would be kept for training purposes, although I have never tried to obtain it from The Royal Free Hospital.

20. Recovery from the actual operation was good but over time my father's strength, rather than improving, appeared impaired. He was unable to fully return to work.
21. In June 1977, his sister offered my parents a break at her holiday home in GRO-C by way of convalescence. I travelled down to spend a couple of final days of the holiday with them. My father was far from well, lacking in energy and disinclined to go out. His colouring was also different, a change that we initially put down to him catching the sun.
22. Once back at home his change in colouring accelerated and it became apparent that he was very jaundiced. This was diagnosed by his GP on 07 July 1977. On 18 July 1977, he was readmitted to The Royal Free Hospital for "investigations of jaundice" and he found out that it was likely he had contracted Hepatitis. It is noted on my father's record "patient developed jaundice on 20 July 1977." I make this record available to the Inquiry as **Exhibit WITN5350004**.
23. On 20 July 1977, the diagnosis of Hepatitis C and B was confirmed. The Royal Free Hospital records state that he contracted "acute hepatitis with deep jaundice".
24. My father was infected with Hepatitis C and Hepatitis B. Please see **Exhibit WITN5350005** and **Exhibit WITN5350006** which detail these diagnoses.
25. My father was ill for many months, he was unable to work and the garage remained closed for over a year.
26. The Royal Free Hospital launched an investigation as to how he had contracted Hepatitis. The Poisons Unit from, we believe, Guys Hospital, visited his garage. My father sometimes did paint spraying on vehicles and so they took samples of various preparations, including paints and tools. They even took items from his home for examination. These were sent away for analysis to, we believe, Guys Hospital.

27. It seemed to us absolutely ludicrous that, having used the same products for the past thirty years in the course of his business, they could be to blame. Nothing was found and eventually he was told that contaminated blood products were to blame for the infection. It seemed that the hospital was almost disappointed to not find my father's garage to be the cause. My father was very relieved that it was not linked to anything from the garage, as he wished to continue working in order to support the family financially and he also loved his work. With hindsight, the investigations were a very thorough attempt to exonerate the infected blood products. I have seen entries within my father's medical notes, detailing the thoroughness of the investigation.
28. We do not know the exact date when information regarding the cause of infection was given to my father, however, I am quite sure that a member of staff informed my father verbally. No letter was sent to confirm the findings and I have found nothing in writing. Nothing is directly mentioned within his records regarding the method used to inform him of the cause of infection. Very little was said and they seemed to give scant importance to the diagnosis of Hepatitis B and C.
29. My father told me and the family about the diagnosis pretty much straight away.
30. Through reviewing my father's medical records, I can confirm that the contaminated blood products were given to him at The Royal Free Hospital between 17 January 1977 and 31 January 1977.
31. Further to this, I can see that the infected blood products used during the gallbladder surgery were: 'Lister Blood Products' administered from 17 to 25 January 1977, please see a record of this at **Exhibit WITN5350007**. 23655 units of 'Elstree Factor VIII Concentrate' with batch numbers: 8CRV857, 8CRV858, HJ1209 and 1232 administered from 20 January 1977 to 31 January 1977, please see a record of this at **Exhibit WITN5350008**.

32. Within the medical records I also found a form regarding a Hepatitis survey investigating the Elstree Factor VIII Concentrate with the same batch numbers that had been administered to my father, please see **Exhibit WITN5350008**.
33. I feel that there is no doubt that he was infected in January 1977 when he underwent the gallbladder operation. The rest of that whole year he was really unwell. The surgery had required the largest input of coagulant that he had ever received. Whether the infection came from Lister or Elstree products, it is not stated, however, it would appear they were subsequently looking into Elstree concentrate, therefore it is extremely likely that it was the Elstree concentrate that was contaminated.
34. In subsequent years the family noted that, at The Royal Free Hospital, the folders containing my father's hospital notes were marked, (in fact, we believe, rubber stamped), "UK Blood Products Only". The family's recollections are supported by a review of my father's medical records. Dr P Kernoff, who was one of the Directors of the haemophilia department, has hand written a note stating that "as from 01/09/85, this patient should not normally be treated with Factor VIII concentrate, particularly commercial concentrate". I have made this document available to the Inquiry. **Exhibit WITN5350009**.
35. We must question the integrity of this instruction. If specific types of blood products were not safe for my father, then surely, they were not safe for other patients? The note directs any decision on use to "a senior member of staff". We wonder what direction had been given to these senior members of staff to equip them to make a decision to administer a blood product that was obviously known to carry such significant risk.
36. I register here the fact that my father did not hold a passport, he never went abroad and therefore, received no medical treatment outside of the U.K.
37. I am quite convinced that, in January 1977, my father received no prior warning of the risks associated with receiving Factor VIII Concentrate, even

though this was the first time he had received it. The family also received no information regarding the risk to him.

38. Little or no information was given regarding the actual infection but rather the emphasis was on looking for sources of infection, other than the blood products. There was a lot of conversation about other sources, which were disproved, as mentioned previously.

39. Some years later, my father and mother were called into The Royal Free Hospital to participate in a research project looking at the risk of passing on Hepatitis and HIV via sexual contact. Notes describe my father as 'not well informed' about these matters. I will detail this project later on in my statement.

40. As a family we believe that significantly greater information should have been provided regarding the implications and management of my father's infected status and the steps that should have been taken to safeguard other members of the family, for example, on one occasion, at Royal Free Hospital, my husband assisted by clearing away my father's congealed blood from a hand basin, using his fingers, only realising that it posed a risk when he saw that the doctor was 'gloved up'. Nothing was said. The doctor did not issue any warning advice.

41. The doctor was aware of Stephen coming into contact with my father's blood, but he was never offered a test for HCV. I believe that the entire family should have been offered a test during this time. We were never given any information verbally or within a leaflet to explain or provide instruction on how to deal with HCV bleeds. When my father had a nose bleed at home one of the family would always assist him.

42. We believe that far more information should have been provided to my father and the family, with far more emphasis being placed on the risks involved. During his later cancer treatment, he was given a sharps box for the home. This demonstrates that, with certain things, the medical staff were very

meticulous and that is why it seems strange to me that the risk of HCV and HBV infection was barely mentioned.

43. In 1997, my father was admitted to hospital and tests were carried out on him because he couldn't pass any urine. The Haemophilia department were involved due to the bleeding risks posed by catheterisation. The following day a young woman doctor from The Royal Free Hospital quite unexpectedly phoned me at work and told me that my father had contracted an infection, but that there was nothing for me to worry about. I was surprised that she had phoned.
44. The following day, the same doctor phoned me back and told me that, in fact, my father had cancer and that it was terminal. I was at work and had answered the call during a research meeting in front of my colleagues. One of my colleagues took me in a cab straight away to see Dad at The Royal Free Hospital. The doctor knew that I was at work and yet had told me this news over the phone. In my practice, I would have asked someone to come in and see me in order to tell them such upsetting news face to face. And this, after she had told me only the day before that he was fine.
45. The Royal Free Hospital were very clear that the cancer was terminal and that there was nothing they could do about the spread. They told me that all they could do is make him comfortable and they didn't give us any time frame. In fact, my father lived a further two years and nine months after diagnosis.
46. For a considerable time, he persevered and remained very active. It was almost like he wouldn't be beaten. The Haemophilia department domiciliary nurse, Patricia Lilley, who was first class, provided a coagulant injection in preparation for each cancer treatment. This was much appreciated.
47. In the early years, when my father was well, he would park up on Hampstead Heath and walk up to The Royal Free Hospital for his appointments. However, as his health deteriorated my husband would drop him off for appointments. Once it got to the point where he couldn't be dropped off anymore and would

need more assistance, the haemophilia department would say “alert us when you get to the barriers”, and, although his appointment was for cancer treatment and not Haemophilia, they would provide a reserved parking bay. This was really helpful and considerate of them and another example of compassionate, first-class care.

48. Although my father had HCV and HBV, neither was listed as a direct cause of his death. In my mind, I cannot see a direct link between his prostate cancer, which spread to lung and bone, and HCV, but I am not a doctor.

Section 3. Other Infections

49. We are not aware of any other infections being transmitted via the Infected Blood. My father never received a letter in regards to vCJD that I am aware of.

50. However, his hospital records indicate that he was tested for Hepatitis G in 1982 and 1995 which I was surprised about as I had not heard of Hepatitis G before.

Section 4. Consent

51. We do not believe that my father was given full information prior to his first treatment of Factor VIII concentrate for his surgery in 1977.

52. We do not believe that he was even aware that an entirely different type of clotting treatment was being administered during his surgery. The focus of all information regarding his surgery related to the use of the borrowed 'laser knife' and the filming of his operation. We do not believe that he was given the opportunity to make an informed decision and to give informed consent.

53. It is clear that the testing of my father with my mother in April 1993 for HCV and HIV was purely for research purposes. It was extremely late in the day to have been of any benefit to my mother. By that point she had been at risk of infection for sixteen years! This was part of the research project mentioned

earlier, in relation to the sexual transmission of HIV and HCV. Again, totally inadequate information was given about the implications of these tests which I shall touch on later in my statement.

Section 5. Impact

54. Receiving contaminated blood which, in turn, caused my father to suffer from Hepatitis C and B, caused him significant physical, financial and psychological impact. The implications of being given infected blood, rippled through all sorts of aspects of his life, and the lives of family members. These effects persisted over the years.
55. The long-term impact of becoming infected with HCV and HBV on my father's life was that his well-being was diminished on all fronts. His strength was reduced and thus he was doing less and enjoyed less. His income was reduced and therefore his life choices were reduced and, in parallel, his stress levels increased substantially. His self-esteem was significantly reduced and he became quite vigilant for health obstacles. Vigilance is in itself debilitating. Through my review of his medical notes, I have discovered an entry dated 1983/4. This note supports the family perception. Riva Miller, The Royal Free Hospital Counsellor and Social Worker writes that, since her last meeting, he "is more cautious and fearful of bleeds and of AIDS. Tries not to have injuries." I make this note available to the Inquiry as **Exhibit WITN5350010**.
56. With regards to physical impact, as previously mentioned, my father was severely debilitated by HCV and HBV. He never regained his previous strength. He was once massively strong. My mother fell once and he scooped her up, placing her on the bed whilst my husband and I would have had trouble trying to lift her jointly. Although, after being infected, he eventually reopened his garage business in North London, over time, he found it too arduous and eventually he reluctantly sold up. Instead, he did smaller servicing jobs, working from his own home or more often at a customer's home.

57. Fatigue was a major side effect of the HCV. Before the diagnosis, my father would always be the one to come to our house and help us out with decorating and gardening, but later it was a struggle for him. Fatigue is mentioned a number of times in his medical notes.
58. He was not clinically depressed but I would say he was disappointed in himself. Looking back now, despite his haemophilia, he always worked so hard. The fact that he could do so much less really impacted on him; it disappointed him and really affected his self-esteem.
59. In regards to the financial impact, at the time of my father's 1977 surgery to remove his gallbladder and his subsequent infection with HCV and HBV, his garage business was forced to close for over a year. This in itself had a major financial impact on him. Later, when it became clear that his reduced strength necessitated a more limited workload, in parallel, his income reduced substantially.
60. My parents were not extravagant people but they would have had far less financial stress had he not been infected. As my father found himself able to do less and earn less, he also worried more about my mother who had poor health and came to need care support. My father was required to self-fund mum's care support. When in 1997 he was diagnosed with terminal cancer his first words to me were not about himself, but rather that he had been fearing becoming ill as he had Mum to look after.
61. In regards to psychological impact, perhaps the most damaging thing to emerge from being infected by contaminated blood was that my father's trust and confidence in The Royal Free team was severely damaged. Prior to becoming infected he had never hesitated to seek help from the haemophilia department and he certainly did not question any advice or treatment that was proposed. After 1977, this complete trust no longer existed. As a family we all liked and admired many members of the haemophilia department and believed them to be excellent clinicians and compassionate practitioners. It is a great shame that, after the effects of contaminated blood became known,

many of their patient relationships must have been significantly damaged, especially, if they personally had no authority over the decision to administer treatment which carried such risk.

62. As previously mentioned, in April 1993, sixteen years after my father was infected, mum and dad received a letter inviting them to attend The Royal Free Hospital for a research project. This study tested the sexual transmission of HCV and HIV. When they received the letter inviting them to attend, neither of my parents had fully understood the implications of being tested for HIV, nor had they been aware that Mum could have been infected with Hepatitis. They had never been informed that they could potentially have HIV. This was a direct result of inadequate information regarding risk dating back to 1977 and just one illustration of the stress caused to all the family.
63. Mum was stricken when she came out of her research interview; it was a traumatic experience for her. She was very upset and she found the whole exercise highly embarrassing. What really upset my mum was at one point they asked her whether she had other sexual partners. She was mortified. It was also very frightening for both my parents as they were not given immediate results. We were all very worried. Mum and dad were totally unaware that she would ever be at risk to HIV or HCV. For sixteen years Mum had had absolutely no comprehension that she was at any risk! This is just one small example of how the damage done by the initial administering of contaminated blood product continued to ripple on through the years. I feel that the harm done by the actual administering of contaminated blood was subsequently compounded by a marked failure to provide adequate information.
64. My mother was tested and cleared for both HIV and HCV. No other members of the family had ever been invited for testing. I make **Exhibit WITN5350011** available to the Inquiry which references to the study and my mother's negative result.

65. My father becoming infected by contaminated blood had a significant psychological impact on my mother. She had obviously always been concerned about my father. Before he was registered as a haemophiliac, he had, in 1964, as previously mentioned, suffered a severe haemorrhage at his garage. He was literally soaked in blood from the waist down and this had been extremely shocking for my mum to see. From that point she had worried excessively about him. However, this worry was significantly reduced after he was diagnosed with haemophilia and placed under the care of The Royal Free Hospital. The team there, as well as providing preventative treatment, directed my parents to bring dad straight to them following any bleed - my mother was enormously relieved. The team engendered confidence. Mum trusted them and was reassured by their presence. However, after his Hepatitis diagnosis, and the realisation that, as part of his treatment, he had received contaminated blood, the confidence that she had built up over time was shattered.

66. I personally believe that stress is the root of all illnesses and so, the shock and stress, may have had a significant impact on her health, perhaps it could also be linked to my mum's dementia. She also worried financially, due to the closure of the garage.

67. My husband and I had always lived relatively close to my parents and had always visited frequently. In the early years of our marriage my father did many jobs for us, helping us to renovate our first home and garden. In later years the tables turned and we undertook many tasks for my parents but working alongside my father. After my father became infected with Hepatitis, and his strength levels were compromised, our commitment insidiously increased. Although he hated his situation, he leant on us. We gave our support gladly but it's necessity also caused us significant restriction. We were not free to make decisions in life without considering the wellbeing of my parents. That included the choice of where we lived. We did not see it as a burden but it was a significant restriction.

68. In earlier years, my husband and I would travel abroad together but we became unable to continue to do this due to our responsibilities as my father's health deteriorated.

69. After my father passed away, I eventually needed to take care of my mum full time. I requested to leave my post as a Research Psychologist with Imperial College. However, as we were in the middle of a research project, in order that we could complete our study, they facilitated my working from home. This was a huge help as it enabled me to work and look after mum. However, when my fixed term contract expired and new posts came up, because of the exceptions they had made for me, I felt like I could not apply which is why I didn't go back. It was a huge disappointment to me. I never felt able to apply for any of the in-house positions.

70. In 1998 I had also been about to start my PHD. The papers had just been prepared. Although Imperial were excellent and really helped me, I needed to give up my career hopes to take care of my mother.

71. In terms of stigma, close family would have been aware of my father's Hepatitis diagnosis. However, it was not mentioned to the wider community such as friends and neighbours. My father's own belated realisation of how he might be perceived had made him sensitive and had knocked his confidence.

72. He was refused dental treatment on two occasions, which I detail below.

Section 6. Treatment/Care/Support

73. It would appear that my father eventually cleared the HCV himself although there is no mention of clearing HBV. To the best of my knowledge, he was not given any treatment for the HCV or HBV. I have not found any records of this either.

74. To be honest, I don't think we were aware of there being a treatment for HCV. Overtime, he got somewhat better and so we thought it just required a time period to recover. No treatment options were ever offered or explained to us.

75. I certainly cannot recall any kind of liver treatment or specialist scans. His routine checks may have included checks on his liver. My husband took him to all appointments during the last 12 years of his life, so he would have known about specialist investigations. However, I believe if he did have problems with his liver then they would have been marginal. I am not medically qualified to comment.

76. My father was never one to decline new or trial medical treatment; originally, he would have gone along with anything that was asked of him. However, there was some hesitance after he had been given contaminated blood. Following his cancer diagnosis, he was offered a place on a trial for an alternative chemotherapy but my father decided not to participate but rather to continue with existing standard treatment. It was the one time that he had not complied with the clinician's suggestion.

77. My father had a very good relationship with the Royal Free nursing team. At one point he even used to take care of one of the nurse's cars. His regard for, and relationship with, the nursing team remained good throughout however, after becoming infected, his relationship with the Haemophilia department in general became perhaps slightly fractured. I think it was disappointment rather than anything else; disappointment that his trust had been misplaced.

78. As time went on my father also felt reduced by the stigma that his diagnosis carried. My father would attend The Royal Free Hospital for his dental appointments, which would be pre-booked. However, on two occasions, he attended and was turned away. They refused to treat him as a direct result of his HCV diagnosis. They told him that he posed a risk and they were not prepared to take it. These were pre-booked appointments and so they could have told him beforehand to save on the inconvenience and embarrassment.

My father was a very pragmatic man; he would accept a lot of things, but he was really upset over this and I think he felt quite diminished.

79. He had never been pre-warned of the stigma surrounding Hepatitis and so it came as a shock to him to be turned away at the dental appointments, especially being located at The Royal Free Hospital. I later became aware that the dental practitioners were given a freehand to refuse patients if they wished, and so they did. I think this all links with the fact that Hepatitis patients were ill informed about risk, not only in terms of initial warnings regarding the risks posed by the blood products, but, just as importantly, they lacked the warning that, once infected, they would be perceived as posing a risk to others.

80. As a family we knew that if my father had a bleeding incident the process was to take him straight to The Royal Free Hospital and they would sort it. For a number of years this gave all the family a new found confidence but following the Hepatitis diagnosis, that confidence was eroded.

81. Over the years, The Royal Free Hospital approached the family on a number of occasions either to request participation in research projects, or to invite attendance at various lectures, however, we were never approached or provided with information, in any form, regarding the kind of risk that hepatitis might pose within the home, or in the event of bleeds. My father was a great one for keeping every kind of correspondence and leaflet. Therefore, I am quite sure if there were any documents provided, he would have kept them and I would have seen them at some point.

82. One example of such an approach occurred during the 1970s. I agreed to participate in a research project conducted by The Royal Free Hospital which aimed to establish a test to tell a woman if she carried haemophilia or not. The methodology was being perfected on known carriers. Later, again in the 70s, my husband and I were both invited to a lecture held at The Royal Free Hospital. It was related to haemophilia carriers and the available options if you were planning to start a family. The advice they gave was that you should be

tested to establish the sex of the baby and, if the baby was male, to consider abortion. It was a frightening thing to listen to. It seems so odd that we were invited to this lecture on the hereditary nature of Haemophilia but never invited to anything in regards to risks of hepatitis in relation to my dad. This really makes me think that they were told to downplay the Hepatitis problem to us.

83. No family member or my father were ever offered any kind of psychological support following the Hepatitis C and Hepatitis B diagnosis.

84. My father was never given any kind of dietary plans to assist with his HCV that I am aware of, as my mum would have followed them.

85. From my experience, as explained at Paragraph 44, I also believe there is a lack of training for doctors in regards to empathising with patients.

86. Very belatedly, in the last years of my father's life, he was invited to an HCV information evening by the Haemophilia Society, to be held on 8 December 1999, but, by then he was too ill to attend and it was too late. I find it ironic that nothing was organised by the hospital and that it was the Haemophilia Society that had to take up the mantle.

87. I would also like to mention that, having read through my father's medical records, I have been surprised at the number of inaccuracies that appear. Dates which are correct in one record appear incorrectly recorded elsewhere. One entry mentions that he 'was fine' following surgery when, in fact, he was far from fine as he had a major fever and an abscess on the surgical wound which later burst open.

Section 7. Financial Assistance

88. In 2011, I received a stage one payment of £20,000 from the Skipton Fund. I had first read about this fund, completely by chance, in the Haemophilia Society magazine. I submitted an application on behalf of my mother who was in my care at that time. Our application was successful but sadly Mum

died just prior to the award being made. In consequence, payment was awarded to me and enabled me to offset some of the care debts that I had incurred through her healthcare.

89. I found the application process straightforward. However, it is a great shame that financial assistance had not been available when my father was still alive as he did not feel financially secure and so he restricted himself in all things.

90. I requested my father's medical records following my engagement with the Infected Blood Inquiry. I received nearly 1,500 pages of medical records and they appear to be complete, as far as I am aware, although we were surprised to note that a section of one record, relating to the exact time period that my father received contaminated Factor VIII, had been torn away, removing part of the information. I make this record available to the enquiry at **Exhibit WITN5350012**.

91. To the best of my knowledge, my father was never told of any kind of financial assistance available to him by the hospital staff. When he was off work due to significant bouts of illness, his income was negligible. Any non-essential purchase for himself was denied, for example, my father had always wanted a greenhouse for his garden, but he would always put mum's care first and the costings for that.

Section 8. Other Issues

92. I hope very much that, in the future, this type of thing will never happen again; I hope lessons will be learnt. I do find it quite difficult to criticise the doctors because, as mentioned previously, many members of the Royal Free Haemophilia department were first class. However, I do feel that some of my father's doctors were extremely remiss in terms of giving him adequate information and allowing him to make an informed choice. I also feel that they were in a very difficult situation. It is with the benefit of hindsight, but perhaps they had an inkling of what was going on but did not speak up? To me, the crux of the matter wasn't only that they knowingly gave patients blood

products that carried the risk of harmful infection, it was that they neglected to warn people of those risks beforehand. Therefore, they did not allow for informed choice. This example of neglect could be construed as negligence.

93. I think my father would be pleased that the whole situation is being looked into through this Inquiry. I am doing this all for my father. He was not a vindictive person and I am absolutely positive that he would not want to be blaming clinicians per se, however he would wish for lessons to be learned.

94. My husband points out that Mr Hancock, at the oral hearings of this inquiry, stated that, if the inquiry should make a recommendation, compensation will be paid. If compensation or similar had been made available to my mum and dad at the time of my father's incapacity it would have made an enormous difference to them and so I sincerely hope that those who still struggle and those that have been bereaved will be given financial assistance.

Statement of Truth

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

Signed

GRO-C

Dated 04-11-21

Table of Exhibits:

Date	Description	Exhibit
Undated (17 January 1977 is referenced within document)	Record confirming the date of Mr Roope's first exposure to concentrate.	WITN5350002
02 February 1977	Letter from Dr Young, registrar to Mr Lewis. Re: Mr Roope's medical history, examination, progress and operation. Notes that gallbladder operation was performed using a laser knife.	WITN5350003
20 January 1977	Record by Royal Free Hospital, entitled 'Hepatitis Survey'. Re: Elstree Factor VIII Concentrate administered to Mr Roope. Details batch numbers, dates and times. Notes that 'patient developed jaundice on 20 July 1977.'	WITN5350004
28 July 1988	Letter from Dr Christine Lee to Dr Davis confirming that Mr Roope developed HCV.	WITN5350005
20 February 1993	Admission record for 'left cataract' surgery. Notes that Mr Roope was 'Hepatitis B positive' at this time.	WITN5350006
17 January 1977	Letter from Michael Bennett, Senior Registrar, Haemophilia Centre to Dr J Davies. Re: record detailing dates and times that Lister Blood Products were administered to Mr Roope.	WITN5350007
20 January 1977	Record by Royal Free Hospital, entitled 'Hepatitis Survey'. Re: Elstree Factor VIII Concentrate administered to Mr Roope. Detailing total number of units.	WITN5350008
01 September 1985	Handwritten note by P Kernoff. Re: use of Factor VIII concentrate in Mr Roope's treatment.	WITN5350009
1983/4	Medical record note by Riva Miller, Counsellor and Social Worker. Re: her observations following their appointment.	WITN5350010

05 May 1993	Letter from Eleanor Goldman, Royal Free hospital to Dr Davies, with reference: EG/gS/110958. Re: summary of Mr Roope's medical review. Notes Mrs Roope's participation in the study of sexual transmission of HCV and her 'negative' HCV test result.	WITN5350011
13 January 1977	Damaged medical record from Mr Roope's files from 13 January 1977 to 31 January 1977.	WITN5350012