Witness Name: Kathryn Johnson
Statement No: WITN3567001
Exhibits: **WITN3567002**
Dated: 25/11/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF KATHRYN JOHNSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 16 August 2019.

I, Kathryn Johnson, will say as follows: -

Section 1. Introduction

1. My name is Kathryn Johnson. My date of birth is GRO-C 1954 and my address is known to the Inquiry. I am retired and I live with my husband. I have 2 adult children who no longer live at home.

2. I am affected by my sister's infection with hepatitis C. I intend to speak about my sister's infection with hepatitis C. In particular, the nature of her illness, how the illness affected her, the treatment she received and the impact it had on her and our lives together.

Section 2. How Affected

3. My sister's full name was Jane Ann Chapman and she was born on GRO-C GRO-C 1949. She was my only sibling and we were always together with our parents. Our parents passed away in 1997 and 2000. Mum was 74 and dad was nearly 81.

4. Jane was infected with hepatitis C after receiving a blood transfusion during surgery for a radical mastectomy.

5. Jane died on GRO-C 2013 from hepatitis C related complications. Advanced decompensated liver disease, liver cirrhosis and hepatitis C virus infection are listed as causes of death on her death certificate which is labelled as Exhibit **WITN3567002**.

6. We were raised in a council house in GRO-C which is located in the greater Manchester area.

7. Jane married her husband David Chapman in the 1960's at the age of 21. She had 2 children; a son named Paul and a daughter named Pamela, who are still living. Jane's husband David died in 2013. He was an ex-police officer.

8. Pamela lives in GRO-C Australia, and Paul still lives in the UK. Pamela is married with children. Paul is GRO-C GRO-C My contact with Paul is very limited to intermittent email communication.

9. Jane and I both worked as nurses. Jane started as a cadet nurse at the age of 16 at Altrincham General Hospital. We both qualified as general registered nurses (SRN). I completed my training at Manchester Royal Infirmary and later trained as a midwife in Bolton, and as a specialist community public health nurse (health visitor) in Cheshire.

10. Jane carried on her career as an NHS nurse and during her career she worked in various nursing and managerial roles.

11. These roles included general nursing and ophthalmic work. She also completed a part 1 midwifery course in the early 1970's. However, she never fully trained as a midwife as she did not complete part 2 of the course, having taken a little time out of nursing when she had her children.

12. In her later years, Jane was a nursing manager at a care home in Buxton, which was called The Pavilion Care Centre.

13. In March 1991, Jane had a radical mastectomy on her right breast at Stepping Hill Hospital in Stockport, Cheshire. During the surgery she had a blood transfusion. She was given 1 unit of whole blood. The consultant for the surgery was a Mr England.

14. In around 2002/3, Jane and her husband sold their home in GRO-C Jane and David spoke about moving to Spain, and they moved to Spain in around 2003.

15. In 2003, prior to moving to Spain, Jane was working as a nurse at Macclesfield Hospital. One day, whilst working in the A & E department of the hospital, Jane complained to the staff of feeling very unwell. She asked one of her colleagues for some Stemetil (an anti-nausea drug) out of the unit drug cabinet.

16. Her colleague advised her that she could not be taking drugs from the cabinet, and as she looked unwell, she was put into a cubicle and a doctor was alerted. The doctor assessed her and took some bloods.

17. Jane phoned me and told me that she had been admitted to a ward in Macclesfield hospital. She told me that the initial blood results showed that her liver enzymes were 6 times the normal range.

18. She also told me that she had been feeling very tired and generally unwell for around the past 3 months.

19. Within a week to 10 days of being admitted, and following her bloods analysis, Jane was diagnosed with hepatitis C. She was still in Macclesfield Hospital when she was diagnosed.

20. When Jane first told me about her hepatitis C diagnosis, I asked her to remind me "what does hepatitis C do to you?". She said that she had been advised that it was a slow process and that it could take 10-12 years for the infection to manifest, causing liver damage, cirrhosis, and possibly liver cancer. She said that the worst-case scenario was a liver transplant or death.

21. From what I remember, I asked Jane if she had ever had a needlestick injury during her career, and she replied with words to the effect of, "yes, a few". I asked if she had reported them via the hospital policies and she said "no", that there was "too much paperwork" involved to do that.

22. I remember the one time that I myself had a needlestick injury, I had to follow the hospital protocols, complete an official incident form and report it as per hospital policy at that time. I think that she didn't follow protocol. However, she was later advised by the medical team that needlestick injuries were not considered to be the source of the hepatitis C infection.

23. The doctors at Macclesfield did more tests to try to ascertain the source of the hepatitis C infection and they told Jane that the amount of damage to her liver meant that the hepatitis C could not have been caused by a needlestick injury. They said that she would've needed to have a lot of blood to cause such liver damage, which they then concluded to have come from the blood transfusion.

24. Jane had never been an intravenous drug user and she did not have any tattoos. When she was diagnosed with hepatitis C, she was asked

whether she had ever taken intravenous drugs, or had sex with people who had sex with men. She was very upset at being asked these questions.

25. By the time that Jane was diagnosed with hepatitis C in 2003, she had been living with the infection for 12 years. Obviously, Jane and her husband GRO-C Jane's children were born before she was infected or diagnosed, when Jane was around 22/23 years old.

26. GRO-C

27. After her diagnosis with hepatitis C at Macclesfield Hospital, Jane was referred to Doctor Prince, a Hepatologist at Manchester Royal Infirmary. She was commenced on Interferon and Ribavirin. She received Interferon injections and Ribavirin tablets.

28. This happened just on the cusp of Jane and her husband going to live in Spain.

29. Because of Jane's diagnosis and treatment, I asked her not to go to live in Spain. However, Jane said that it was David's dream to go and live in Spain when he retired. Jane was the kind of person to do what her husband wanted, so they went to live in Spain in 2003. This was just a few months after Jane's hepatitis C diagnosis.

30. GRO-D

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35. In around January 2013, Jane rang me one day when I was at work and told me that she had been in intensive care in Spain for a few days. She had hepatic encephalopathy and had been unresponsive. She told me that the doctors saved her life.

36. In around March 2013, whilst living in Spain, David GRO-C GRO-C During this time, David GRO-C GRO-C GRO-C passed away. Jane was an

in-patient at the same hospital at the time. She was too ill to attend David's subsequent funeral.

37. A few weeks after David's death in GRO-C 2013, I had to urgently fly out to Spain to visit Jane to assess the situation myself. This would have been in April 2013. I remember she looked very frail and she said that she was feeling really ill.

38. Around the time that I went to Spain to visit Jane, I myself had recently been quite ill and was consequently diagnosed with left sided Meniere's disease. I was diagnosed by an ENT consultant at Manchester Royal Infirmary in October 2012.

39. I had months of ill-health preceding this diagnosis where I experienced bouts of severe vertigo, during which I was unable to stand, lost my balance, and was unable to move or see. I couldn't think straight and I had to lie completely still, often for hours, not moving my head at all. I would vomit and experience gastro intestinal problems. On one occasion the episode lasted for 18 hours and I thought I was dying.

40. I had an MRI scan in January 2013 to rule out a brain tumour, and I was then also diagnosed with a left sided acoustic neuroma (benign tumour on my hearing nerve). I had a series of treatments for the Meniere's, with regular further hearing tests, and they initially monitored the tumour by MRI scan every 6 months to assess any growth. They said not to worry as the tumour was quite small, but I would now be monitored for the rest of my life. By now I was also experiencing continuous tinnitus in my left ear, with some resulting hearing impairment.

41. I had to attend Manchester Royal Infirmary regularly for a series of steroidal injections through the eardrum with a spinal needle to try to reduce the symptoms of the Meniere's disease. This had good results for me eventually. I had a series of treatments over 18 months while Jane was ill. My illness meant that I was not in any condition to look after Jane. Also, during this time, I continued working as a part-time health visitor as

further recent state pension changes were introduced by the government, greatly increasing and affecting the age at which I could claim my pension.

42. In April 2013, before leaving for the airport to fly to Spain to see Jane, I suddenly had a thought that I would need an urgent plan if I found her to be so ill that she would need to be repatriated back to the UK. I quickly googled the internet to research what options I may have. I completed some online forms for a private air ambulance service (this was the International Air Ambulance Service) and spoke to them directly by phone regarding the possible situation with Jane's health.

43. When I arrived in Spain that day in April 2013, what I saw was dreadful. Jane was lying in bed and she looked like a little old lady. She looked terrible, like she was dying. She was grey. When I saw the state of her, I knew that I couldn't leave her in Spain. I was also concerned as her son Paul had gone to Spain himself a few weeks earlier with the intention of looking after Jane, GRO-C GRO-C GRO-C

44. There was no way that Paul could care for her. GRO-C GRO-C Jane wasn't eating properly. She was unable to get out of bed without help, not least to get to the toilet or to make meals. There was no care for her in Spain as they don't have community nursing care. Family members are expected to care for their relatives.

45. I could not stay in Spain to care for Jane, especially with my recently diagnosed illness and my own husband and family living in the UK. Jane had her friends, but in my opinion, it would not have been appropriate for her friends to provide the intimate personal care she needed. There was also the risk that they may face from contracting hepatitis C themselves via body fluids/vomit/etc. I thought she would be best looked

after at home in England, back within the NHS system, and nearer to my support and her friends in the UK.

46. I made a call to the air ambulance company who I had contacted beforehand. Given how ill she looked, I considered that she would not be liable for, or be able to be carried on, a normal commercial flight. The company (International Air Ambulance) said that it would cost around £20,000 to repatriate her. She would be offered a private air ambulance with a doctor and nurse, a private ambulance from Murcia Hospital to San Javier airport, and another private ambulance from Manchester airport directly to Manchester Royal Infirmary, where she was previously treated in the UK.

47. Jane had self-discharged from Murcia Hospital on the day that I arrived at her home in April 2013 (which was a Friday), as she had told the staff that I was coming and that I would look after her. At the hospital in Murcia she had been receiving a different kind of treatment for hepatitis C to the treatment she had received in the UK. I'm not sure what it was. I know that as part of her treatment in Spain, she had been receiving enemas for the bowel symptoms of hepatitis C.

48. I thought that this seemed to be a rather out of date practice according to the current NHS treatments that were available at the time. As Jane didn't speak Spanish, every time she was transferred to hospital in Spain she would need to pay a local translator 20 euro an hour for medical terms to be translated for her, and for the translator to accompany her to appointments.

49. Prior to being in hospital in Spain, Jane was flying to the UK regularly to receive treatment at Manchester Royal Infirmary. This was because the flights were very cheap at that time. She would fly home to the UK about once a month and either stay with myself or a friend while she received treatment.

50. Eventually the cheap flights stopped and that is when she and David permanently took up residency in Spain. For a while in Spain, she was on some kind of medication for hepatitis C, but this was eventually withdrawn as she was experiencing some side-effects /skin problems and the medication was making her feel even worse.

51. Jane was on the liver transplant list at Murcia Hospital, which was about an hour away from where she lived. She was required to be on the transplant list at this main hospital as the local hospital was for Spanish people, and the main hospital at Murcia had a specialist hepatology department.

52. She was provided with a dedicated mobile phone from the Hepatologist at Murcia Hospital. They said they would call her if a liver became available. However, for some reason, Jane had handed this phone to a friend for safekeeping, and unfortunately, when the call came from the hospital for her to attend asap, as a possibly suitable liver had become available, the friend missed the call. Jane was not informed so the liver went to someone else.

53. In around 2011/2012, Jane received another call and this time she got an offer for a transplant. She had to get to the hospital for 7am the next morning for the liver transplant. I waited all day for news from her husband, but by the evening, after not receiving any calls from David, I phoned the home number to see if all was well. I expected David to be home and to tell me she was recovering in intensive care by that point. However, David said that she was in bed at home. He handed the phone to Jane and she explained to me that the liver had gone to a man from Madrid.

54. The hospital said that they would keep Jane on the transplant list. However, by the time I went to see her in 2013, I became very aware that she may not be well enough for a transplant, as she was very frail and weak.

55. I had seen her 8 months before in June 2012, as she had returned briefly to the UK and was regularly having fluid drained off her abdomen ('paracentesis') to relieve abdominal ascites. She also had oesophageal varices and moderate cirrhosis. She was looking very swollen at this point with the ascites and appeared to have gained a lot of weight.

56. When I realised I would need to get Jane back to the UK from Spain in April 2013, there were some difficult issues with releasing funds from her Barclays bank account in order for me to organise the air ambulance. I needed her Barclays account number and code/password to organise the transfer. She was so ill she was unable to maintain a conversation or to think where she had the code.

57. I was personally trying to ring Barclays via her Spanish mobile phone to get help and to organise this. A couple of Jane's friends took me to the nearest Barclays branch one day which was over an hour away. On arrival at the bank, I was told that the Barclays in Spain was not the same as the British one. I was so exasperated by now. I was stressed out and desperate to get my sister back to the UK asap and was losing sleep myself, remaining conscious of my own ongoing health issues.

58. I knew that I had to get Jane out of Spain and that if I left her there she would die. The whole situation of trying to organise the air ambulance out of Spain was extremely emotionally and physically stressful. I was completely exhausted, I thought that I would drop dead myself by the end of the week.

59. I even urgently emailed my MP asking for assistance, and advising her that my sister, who was an ex- NHS nurse, was in a dreadful situation in Spain. I asked for urgent repatriation help. I never had a reply.

60. I eventually managed to get Jane to remember her correct bank password code. The air ambulance company told us that if we transferred the fees immediately over the phone they could get a flight

out to Spain to retrieve us both at 3pm the next day. They also arranged for the medical handover between the Spanish and UK hospitals on the ward at Murcia Hospital where Jane was. She was to be transferred into the care of the UK doctor and nurse at her bedside.

61. It was like one of those nightmares where you are running from a lion and everything is catching up with you. I was so emotionally stressed out. That whole week was like a never-ending total nightmare. I then had the added anxiety of trying to locate Jane's E111, which took a few hours, and when I did I was so relieved to find it was still valid, as Manchester Royal Infirmary had stipulated that this was essential for her being accepted back into the system and into the NHS.

62. I had managed to get Jane urgently re-admitted to hospital in Spain when I saw the state of her, but that whole week was so physically and emotionally upsetting for us both. Whist in the Murcia Hospital A & E department for her re-admission (the day after I had arrived and saw the state of her as mentioned) I explained to the A & E doctor my plans to get Jane repatriated to the UK for medical attention. He commented that she would have a "better chance" of life because of my decision.

63. A moment of self- belief crossed my mind and I remember feeling so elated that I had managed to have her re-admitted to Murcia Hospital, so the private International Air Ambulance staff could collect her directly from the ward at Murcia when all arrangements were formalised.

64. Jane's friends in Spain were so supportive with my plans and so helpful with everything. Jane had made friends in Spain from singing in an award-winning local ladies barbershop music group. They travelled all over Spain to sing in competitions, winning most of them.

65. The air ambulance company arranged for a private ambulance to transport Jane by stretcher from Murcia Hospital, accompanied by myself, as well as the UK doctor and nurse. We were taken to San Javier airport and boarded the small, medically equipped, prop plane (King Air

2000). The doctor and nurse accompanying us on the flight were British and they checked Jane over at the hospital before we left, and had a thorough medical handover from the Murcia Hospital team.

66. The staff on the air ambulance were; 1 pilot, an intensive care doctor from Manchester Royal Infirmary, and an intensive care specialist nurse from Exeter Hospital. The flight had left from Exeter Airport (the doctor had been called to the case by the air ambulance company whilst he was on holiday in Cornwall). The flight left San Javier airport in south east Spain at 3pm that day.

67. Jane was placed on a stretcher and was connected to appropriate medical equipment. When we arrived at Manchester airport, Jane and I were immediately transferred by a private ambulance, and Jane was admitted straight to a bed in Manchester Royal Infirmary at 9pm. I was so relieved when we got back on UK soil.

68. When we landed at Manchester airport I felt such relief that I could now relax a little. I'd survived one of the most awful times of my entire life. I bought Jane a little toy crown, as I told Jane she was "Queen Jane", and placed it on her head. "Queen Jane" was a nickname I had for her.

69. By the time Jane arrived back in the UK she looked like an 80-year-old woman when she was only 63. She didn't look like my sister anymore. Manchester Royal Infirmary said that they would be building up her physical health with a view to improving her status, and a care plan would be put in place for her to be on the liver transplant list.

70. Jane was transferred a number of times by NHS ambulance services from Manchester Royal Infirmary to St James Hospital in Leeds (the north west regional transplant hospital) when she returned to England. She needed regular medical reviews and monitoring of her condition to assess suitability for a possible liver transplant. After returning to England she did not go back to Spain, or become well enough to be

discharged, whilst awaiting a transplant. She remained in hospital and was then transferred to a hospice where she died.

71. She needed to be in hospital as she had deteriorated to a point where I could not have cared for her. She couldn't go to the toilet on her own, and she had chronic diarrhoea. She was nauseous and vomiting a lot, and she had oesophageal varices. There was a danger that these varices could rupture with immediate associated life-threatening consequences.

72. Jane was accepted on to the transplant list at Leeds Hospital after three months. When she was in hospital in Leeds I would get a train to visit her, rather than drive all that way, as my own health was still rather fragile. Whilst she was in Manchester Royal Infirmary, I went to see her around 2-3 times a week, mostly after finishing work (I was a health visitor in Wilmslow at that time).

73. She did get on to the transplant list just before her 64th birthday. She was 64 on GRO-C 2013 and I feared that it could be her last birthday. I managed to arrange with Manchester Royal Infirmary for her to come out of hospital for part of the day for her birthday garden party, which I had planned and organised for her as a special good luck event.

74. It was an absolutely beautiful day. Her daughter Pamela came over from Australia and we had a garden party in my back garden. I bought her a beautiful dress to wear and she sat out in the garden like "Queen Jane" again, which as I mentioned previously was a nickname I had for her. The hospital released her from the ward for 4 hours and her daughter took her to the hairdressers to get her hair and make-up done for the party. It was such a wonderful and special day.

75. I arranged for her UK friends (the ones I could contact from her diary) and a cousin that Jane was close to (and his family) to join us for her party. But I still had this overbearing feeling that it would be her last

birthday and I was so worried that she wasn't going to get a life-saving transplant.

76. Not long after this she deteriorated even more. Manchester Royal Infirmary rang me one day and told me that she had been unresponsive when a staff member had gone into her room on the ward. She was in intensive care for 3 days with hepatic encephalopathy once again.

77. After she recovered sufficiently well enough from that episode, Jane was then transferred back to Leeds for further reviews in light of her recent set-back.

78. One day in October 2013, a transplant specialist nurse from Leeds Hospital rang me at my home, asking to speak to Jane. I was concerned that the nurse was unaware that Jane was actually an in-patient in Leeds Hospital (from where the nurse was calling me) and that she should surely have known that, or at least have been informed by the medical team of that fact.

79. She went on to discuss discharge planning with me. I told her that as a nurse myself I couldn't see Jane being discharged any time soon as she was so ill. The nurse informed me that they can do part liver transplants from live donors within the family. A few days later I was contacted by one of the doctors on the medical team who told me that Jane had requested to be taken off the liver transplant list as she felt that she was now too ill.

80. They requested that I come to the hospital as they said they were just about to have that conversation with her anyway. Jane's blood group was B negative and I am B positive. I remember that Jane had previously showed me a booklet about this (a booklet about live donors). My husband said to me words to the effect of "you're not doing that, you could die, and she is probably going to die anyway". I also had my first grandchild and another grandchild was due in a few months' time.

81. I rang Jane's daughter in Australia and recounted the conversation with the Leeds transplant specialist nurse to her. She said that she could not be the donor, as it would require her talking 3 months off work to travel from Australia to have the operations. She also had 2 teenage children (who were not her husband's), and she felt that she would be unable to leave them in the care of her husband and his family for that length of time.

82. I didn't feel particularly pressured to be the donor when I received the call. I just felt very stressed again and that maybe Jane would feel I was letting her down. I felt really awful that I was alive and that I could help her, but medical issues were stopping me. I had read (in the booklet I mentioned) that you had to be under 60 years of age and in good health to be a live donor. I was 2 months from my 60th birthday. I just felt that I couldn't do it, but I was torn inside at the thought that I wouldn't be able to help her. In addition to this, Jane's daughter was actually B RH negative blood type, so she was a better match for her.

83. The nurse said that it didn't matter if I was not a complete rhesus match, that the donation could be treated anyway so that it matched. This just made me feel worse. It really upset me again emotionally.

84. Jane continued to deteriorate. In early GRO-C 2013, after I had tried to find a nursing home local to my own home for Jane to be discharged to, the Leeds team arranged for Jane to be transferred to Macclesfield Hospice, much nearer to my home. Here she would receive the 24 hour care she needed. She would be quite lucid at some points and have relevant conversations with me, but on other occasions she was confused and would often be sleeping when I visited her. Jane knew she was going to the hospice and that the end would come. She would cry and say that she didn't want to die and that it was all so unfair.

85. When Jane was admitted to the hospice I felt very relieved but also very disappointed. I was emotionally helpless and unable to reassure her as

she knew she was getting weaker. She knew that she was going to die, and I thought what a horrible thing (to know that the worst outcome of this awful disease was now inevitable).

86. Jane was in the hospice for around 8-10 weeks until she passed away. I would go and visit her very often and would occasionally stay overnight in the bedroom provided for family by the hospice. Jane shouldn't have been dying, it wasn't her fault. She kept saying to me, "this isn't my fault, it's all so unfair". When she was in the hospice she also told me, "Kath, I don't want to be here anymore". She wanted to die by that time.

87. Jane's daughter GRO-D GRO-D Jane and David did however travel to see their daughter and their two grandchildren in Australia a few times before both Jane and David became seriously unwell. Jane's daughter attended her father's funeral in Spain in GRO-C 2013. To me, it seemed like they were not that close, but they did Skype often so I suppose the problems were due to the distance and rising cost of travel between all these countries.

88. I did receive occasional emotional support from the hospice. One of the doctors would counsel me sometimes and the consultant was very professional and caring.

89. The hospital chaplain was not available on one or two occasions when Jane felt she wanted to talk, so a lay preacher from the United Reform Church in Knutsford, Cheshire, was called to attend on her. He came and talked to Jane, though she wasn't particularly religious at all. She just needed comfort and a caring person to listen and give her courage to face her death with dignity.

90. One of Jane's friends came to visit her and we all held hands and had an especially comforting chat with the preacher. He said some very nice, comforting and spontaneous things. They were not particularly religious,

they were more soothing, because as I said before Jane was not really religious.

91. Jane needed to have fluid drained off her abdomen (paracentesis) a few times during the last few months, and whilst she was in the hospice I could see she could hardly breathe. On one particular occasion she was struggling with this.

92. The staff in the hospice said they couldn't do the paracentesis at the hospice as they didn't have the expertise, so I had to work hard to persuade them to help her. So, they contacted the ward at the nearby general hospital (Macclesfield District General) and in agreement with the hospital they transferred Jane to Macclesfield by ambulance in November 2013 for a few hours for the paracentesis. They drained 5 litres of fluid off her abdomen. I was allowed to stay in the room. Jane was mostly sleeping.

93. At the hospice they were aware that Jane had hepatitis C, so they took special precautions as per hospital infection control measures/policies, so as not to contaminate equipment or staff.

94. Toward the end, Jane would ask to eat sweets a lot. I think this was because of her liver problems, due to the liver damage, which I believe was causing the liver to be unable to store glycogen for energy (the metabolism of sugar was affected).

95. In those last days of her life, Jane went for about 10 days without food or water. My view was that the hospice had put her on some kind of "end of life pathway" which I understood to be akin to the "Liverpool pathway" at the time. They sedated her so that she didn't know what was going on, which was within Jane's personal wishes, as a few days before they sedated her Jane said, "tell them to just put me to sleep, I don't want to be here, I don't want to know what is happening".

96. The doctor advised me to take all food and water that she had in her locker and in her room away from her. They said that if she was an 80-year-old she would have died sooner, probably within 3-5 days, but it was around 10-12 days later before Jane passed away.

97. Jane died on GRO-C 2013 at 7:36am. I was by her bedside at the time and had stayed constantly with her overnight in the hospice, having been called at 12 midnight by the senior night nurse.

98. I promised Jane I would be with her when the time came for her to die and that I would hold her hand.

99. On the day Jane died, I'd had a phone call at midnight (on the GRO-C GRO-C to come to the hospice asap, as they thought Jane was close to passing away. When I went to see her in the hospice she was Cheyne-Stokes breathing (which I understood from my nurse training). Jane was being 'reverse-barrier nursed', so we had to wear plastic aprons and latex gloves whilst in her room to avoid infection. She was breathing quite noisily and irregularly. She was unconscious and continued through the night in this way.

100. I noticed just a few minutes before she passed away that her heart was fibrillating beneath her nightdress and I called for my (female) cousin, who was also in the room all night with Jane and myself, to go quickly to the ward office to alert the nurses as I knew she was about to die. Then suddenly as Jane passed away, dark blood gushed out of her nose and mouth. The nurses were in the room quickly and I had to leave my sister to their care as she lay in the bed. The hepatitis C had totally wiped out my sister's innocent life and stolen her dignity right to the end.

101. I managed to phone Jane's daughter, making sure that she was not alone, as I told her of her mum's death. Pam said her husband was with her, so I told her the awful news.

102. The worst part about Jane's death for me was that I had lost my dad and my mum (both to other medical reasons) years before and now my sister was gone too, but Jane didn't have to die at such a time and in this way, and she would never have had the contaminated blood if the blood had been screened as had been recommended by medical experts in the UK at the time (in the 1970s/1980s etc). So, it was a most terrible end to Jane's life and so utterly unfair and preventable.

103. The coroner decided that the "conclusion" of Jane's death was 'Misadventure', as she was given the 1 unit of blood to save her life during the mastectomy surgery and they didn't know it was infected. I think this was wrong, as the fact that the blood had not been screened for years was in the public eye for many years.

104. The coroner's office rang me after Jane died in GRO-C 2013 and told me that blood products only began to be screened in September 1991.

105. There was an attempt to trace the donor of the blood that Jane received but they could not be traced.

106. I am not aware of any other transfusions that Jane received during her life, besides the transfusion she had when she underwent her radical mastectomy. I knew she had some stomach problems years before, but she never mentioned any transfusions. As far as I am aware, she was fine during both episodes of childbirth and didn't require or receive any blood or blood product transfusions.

Section 3. Other Infections

107. As far as I am aware, Jane did not receive any infection or infections other than hepatitis C as a result of being given infected blood products.

Section 4. Consent

108. I do not believe that Jane was tested or treated without her consent, without being given adequate or full information, or for the purposes of research.

Section 5. Impact

Physical and mental impact of hepatitis C

109. Jane was quite healthy up until she was diagnosed with hepatitis C.

GRO-D

110. She also had an unusual blood vessel in her stomach years before, for which she had surgery at the then Withington Hospital, Manchester.

111. When Jane emigrated to Spain we stayed in touch, mostly by phone calls. I visited her a couple of times. On a few occasions she reported feeling nauseous and tired to me. If she went to her singing group she would often be so tired that she would have to go home.

112. I knew that Jane had developed cirrhosis before she went to Spain. I went to the Murcia Hospital with her once for one of her appointments and the doctor asked her about her alcohol intake as she told her that because of the cirrhosis caused by the hepatitis, she would need to stop all alcohol. As a nurse, Jane knew this, and she had been advised about it previously.

113. When I saw Jane in GRO-C 2012 at my son's wedding, she looked overweight. However, toward the end of her life she had lost a lot of weight. Just before she passed away, she looked like she had cancer. A healthy weight for her was 10 stone, but she must have gone down to

around 8-8.5 stone. When Jane was of a heavier build she said that it was her abdomen swelling due to the ascites.

114. For many years, Jane had portal hypertension (due to the chronic liver disease) and resulting oesophageal varices. In the last year of her life at least, fluid collected in her abdomen (ascites). The oesophageal varices could have ruptured anytime, so the doctors were scanning and measuring the size of these blood vessels at her regular hospital appointments, initially at Manchester Royal Infirmary, then Spain and again at Manchester Royal Infirmary and Leeds.

115. She also had cirrhosis, and because of this, and the other problems caused to her liver by the hepatitis C infection, she needed a liver transplant. As I mentioned previously, she was on a waiting list for a liver transplant. In Spain, at one point, she was only 6 points off qualifying for a liver transplant. At this time, she told me that she had a plan that she would drink more wine so that she could get more 'points' and have the transplant.

116. Jane didn't stop drinking alcohol after her hepatitis C diagnosis. She was not an alcoholic, and didn't drink excessively, but she wasn't a teetotaller either and enjoyed mostly a glass of wine. In Spain that was the life they lived and it was Jane's choice to move to, and live in, Spain surrounded by that lifestyle.

Physical and mental impact of the treatment

117. As I mentioned previously, Jane started treatment under Doctor Prince at Manchester Royal Infirmary when she was diagnosed with hepatitis C in 2003. This consisted of Interferon injections and Ribavirin tablets.

118. Jane would attend the hospital to have the Interferon through an IV and to take the oral tablets.

119. When she moved to Spain she would fly back and forth between England and Spain on a monthly basis to continue the treatment she had started at Manchester Royal Infirmary. She would also have liver scans when she was home, and they would assess her oesophageal varices and the level of cirrhotic liver damage.

120. Jane said that the treatment was similar to chemotherapy. It made her feel a bit tired and nauseous. The hospital would always advise her to delay flying back to Spain for at least a couple of days after receiving treatment.

121. After being in Spain for a couple of years, she stopped this travelling to and fro, and took up Spanish residency which enabled her to use treatments in Spain. I know she was put on some sort of medication for the hepatitis C in Spain but I'm not certain what it was.

122. She was taken off the treatment after a while as it made her feel very ill. I know she received enemas as part of her treatment in Spain, which I thought was unusual and outdated compared to the NHS treatments available. I mentioned the enemas to the doctors at Manchester Royal Infirmary and they commented with words to the effect of "that's very out of date, we don't do that".

123. Jane never cleared the hepatitis C infection.

<u>Stigma</u>

124. Jane's friends in England knew about the infection. I'm not sure whether her friends in Spain knew the full extent of the disease.

125. I don't think she had any adverse response when she told her friends about it.

126. When Jane was on the ward at Manchester Royal Infirmary, she was often placed in a separate room, and some of the time she felt as though staff were ignoring her.

127. There was one occasion at Manchester Royal Infirmary where she had some dental problems, and she was taken to Manchester Dental Hospital (which was nearby) in a taxi while still wearing her nightdress, dressing gown and slippers. She told me that the taxi that took her there and just dropped her off outside the front of the dental hospital. She did not have an escort from the ward with her.

128. She told me afterward that she was in a lot of discomfort at the time. I can't remember whether she was given treatment by the dentist on that occasion, but she was meant to be kept in the best condition for a possible transplant. Any dental infection could have had adverse problems in that respect and Jane was very aware that this could have consequences for her chances of getting a transplant. I mentioned this to the ward staff at the time.

Impact on family members

129. I was the family member who was closest to Jane during all this time. Not putting myself forward as a live liver donor for Jane created a lot of emotions in me and it was a very difficult time for me and my own family to see me supporting my sister, but not in the way that she may have wanted herself.

130. The way that Jane died, and the suffering of her final days, was the worst part for me.

131. Jane's son Paul was not able to cope very well with the situation at all. The last email I sent to him was around 10-12 months ago to inform him about the new Contaminated Blood Inquiry and my own registration as an interested party. He responded back by email with "Aunty Kath I'm in tears, I can't deal with this".

132. I told him that if he was so upset and affected then he should see his GP for advice and support. I also told him that we needed to find out the

truth, and that someone or some persons who denied the problem existed, or had blocked or refused the screening of the blood (for reasons of cost) back in the 1970's, 80's and early 90's, needed to be brought to account for their negligence, and for going against medical advice. I have never heard back from him since that email. I don't know where he is now. He could be anywhere.

133. Besides her son, daughter and myself, Jane had no other close family. Our parents died years ago and Jane was a widow, albeit of a few months, before her own death.

Financial impact

134. In terms of financial impact, there was the cost of £20,000 that she had to bear for the air ambulance back to the UK. Half of this was reimbursed by the Caxton Fund.

135. Jane's estate did recover half the cost of the International Air Ambulance fees from the Caxton Fund, after I informed them of the situation of her illness and her medical repatriation costs. The cost of the funeral was also mostly met by the Caxton Fund after her death.

136. Jane also missed out on years of intended salaried nursing practice after she became ill with hepatitis C.

Section 6. Treatment/Care/Support

137. I am not aware of any difficulties or obstacles Jane faced in obtaining treatment, care and support in consequence of being infected with hepatitis C.

138. I am unsure whether counselling or psychological support was ever made available to Jane.

139. I was the only person responsible for dealing with everything that was happening with Jane, as my husband was not close to Jane, her daughter was in Australia, and her son GRO-C GRO-C A couple of my close friends also had breast cancer at the time.

140. I didn't get any particular psychological support or counselling. I did not go to see my GP about it either, though my GP knew about Jane as I had registered Jane as a patient with my doctor's surgery, and had given my own address as a 'care of' contact address as soon as I had got her flown back and repatriated in the UK.

141. Toward the end, and when Jane was in the hospital, I didn't feel like I needed psychological support as I knew what was coming, and had psychologically self-prepared myself for months regarding the inevitable consequences of the hepatitis C infection.

Section 7. Financial Assistance

142. I am aware that Jane received 2 payments earlier on. She received an initial payment of £25,000 not long after she found out she was infected with hepatitis C. I think this was from the Caxton Fund.

143. She also received regular payments from the Skipton Fund. I think it was a monthly allowance of £1,300 tax free.

144. She later received another £25,000, which she only knew about from me. I told her that I had seen an article in the paper, or something on the internet, or the television, which said that that the Skipton Fund was paying a further compensatory amount, and that she should enquire. She received the second payment of £25,000.

145. I think that the Caxton Fund paid for about 75% of Jane's funeral costs. I phoned the Caxton Fund and advised the person taking my call that

Jane was very ill and was not going to live. It was agreed they would pay for part of the funeral costs.

146. When Jane was in the Macclesfield Hospice, she decided that she wanted to change her will so that GRO-D GRO-D in a bad way. A notary solicitor came to see her with his legal assistant from a firm in Liverpool, recommended to Jane by a solicitor friend of Jane's. But the day they attended, Jane was very ill and was unable to stay awake so the visit was abandoned. Legally, they said they were unable to carry out the change. The fees for the notary for two hours plus expenses amounted to over £600.

Section 8. Other Issues

147. I am really happy that this Inquiry is happening.

148. As I mentioned previously, the worst part about losing Jane was the way she died and that her death was totally unnecessary.

149. She and others like her should never have contracted the infection in the first place if the person/people responsible for this national disaster had heeded the medical information given to them at the time.

150. Screening the blood was deemed to be too costly from my own memories of the situation at that time. The consequences, and the number of deaths and number of affected families torn apart by the outcomes of the very poor decisions the policy makers made, are being lived out and suffered by people across the UK every day, and to this very day. Jane was an unfortunate victim of a most preventable NHS disaster. She would say that everything I have done for her, and told you about, she would have done so herself if she had been alive to do so.

151. I was so worried and disappointed when Leeds Hospital rang me and told me that Jane wanted to be taken off the transplant list. The fact that

the Leeds Hospital transplant specialist nurse didn't know Jane's whereabouts when she phoned me that day to speak to Jane (who as I mentioned was in a ward in that hospital at the time) was beyond my comprehension, considering the number of reviews, admissions and meetings about Jane that person must have had.

Statement of Truth

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

Signed GRO-C

Dated 25/11/2019