Witness Name: Jane Lindley
Statement No.: WITN6153001
Exhibits: **WITN6153002 – 005**
Dated: 20 April 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JANE MARGARET LINDLEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 29 March 2022.

I, Jane Margaret Lindley, will say as follows: -

Section 1. Introduction

1. My name is Jane Margaret Lindley. My date of birth is GRO-C 1944 and my address is GRO-C

2. I am a widow and live alone following the death of my husband Cyril in 2019. I previously worked as a wine consultant for a drinks retailer, before taking early retirement through ill health, caused by hepatitis C (HCV) and associated issues in 1994 aged 50. I have two sons and a daughter, 7 grandchildren and 5 great-grandchildren.

3. I intend to speak about my infection with HCV, liver cirrhosis and the subsequent liver transplant I received. In particular, how I was infected,

the nature of my illness, how the illness affected me, the treatment that I received and the impact it had on me, my family and our lives together.

4. I have been assisted in providing this statement by my daughter, Sarah. My daughter is an occupational health nurse who has assisted in my care throughout my illness and has been able to help me with this account.

5. The anonymity process has been explained to me and I am happy for my name to remain visible on my statement.

Section 2. How Infected

6. Up until June 1990 I had enjoyed good health. Other than a bout of scarlet fever when I was about 15 years old. On 4th June 1990 I attended hospital with a pain in my left hypochondrial area. This was found to be a cyst on my left kidney that needed to be removed straightaway. This was duly removed in an operation at Bassetlaw Hospital, Worksop on June 6th. Whilst under general anaesthetic and during this surgical procedure, I was given two units of blood by transfusion.

7. At no time prior to the administration of blood was I informed that a transfusion may be necessary or that there was any risk, however slight that I may contract HCV, or any other form of infection. I was given no information whatsoever about the risks involved in having a transfusion.

8. Prior to this, I had only been admitted to hospital for the births of two of my children in 1967 and 1971 and my hysterectomy in 1975. During the birth of my son Stephen in 1967 I received a blood transfusion. I also had a blood transfusion at the time of my hysterectomy. Therefore, in my life, I have had a total of three blood transfusions.

9. I recall that almost immediately after my discharge from hospital, I began to suffer abdominal pains. This continued for some months and in

October 1991 I was diagnosed as suffering from gallstones and as a result I underwent a cholecystectomy operation at Bassetlaw Hospital to remove my gall bladder. I did not receive a blood transfusion on this occasion.

10. Following my discharge after the cholecystectomy in October 1991, I again began to suffer from upper abdominal pain. I also felt nauseous and extremely lethargic and generally, I felt unable to recover from the surgery.

11. I had assumed that the surgery had naturally made me feel low but I then had a conversation with a friend who had also had gallstones removed and she told me that she had felt markedly better immediately after the operation and could not understand why I was still I such discomfort and feeling so lethargic.

12. This made me suspicious, that something was amiss. I had no idea or notion that I may have been infected from my blood transfusion. I actually thought that I may have cancer.

13. I made numerous visits to my GP, Dr Foster, complaining of a variety of ailments including extreme fatigue, pain in my middle and lower abdomen, nausea and dizziness.

14. During the 2 or 3 years that followed my operation and due to my job, I decided to learn more about wine and undertook a course to become a wine consultant. I should point out that I was not a habitual drinker of any alcohol, in my professional, personal or social life. I drank only very occasionally. In 1993, as part of this course, I went to the Champagne region. Upon my return, I felt very ill, with symptoms including nausea, fatigue and diarrhoea.

15. In 1994, I went on holiday to Italy with my husband Cyril. I experienced similar symptoms, particularly fatigue and just generally feeling down and fed up. My husband got frustrated with me because I didn't feel like doing anything during this trip. I had unusual and inexplicable symptoms,

including a redness on my hands, itchy skin and diarrhoea. The worst thing, though, was the debilitating fatigue. I had convinced myself that something was seriously wrong with me and I resolved to visit the GP immediately upon my return home.

16. I saw my GP, Dr Foster, who was based at Crown House Surgery, Retford. He asked me about my alcohol intake. I was quite shocked at this question and I told him that I only ever consumed alcohol on an infrequent social basis. Dr Foster referred me for liver function tests. These showed significant abnormalities and I was referred to Dr Corbett, a general medical consultant at Bassetlaw Hospital.

17. Dr Corbett took further liver function and blood tests. I was not told that I was being tested specifically for HCV, I simply assumed that they were general tests on my liver.

18. I would like to make it clear that I have no complaint against either Dr Foster or Dr Corbett, they were both marvellous with me.

19. Soon afterwards, Dr Foster came to visit me at work. It happened to be on my 50th birthday. He asked to speak to me privately, so we went to my office where he then informed me that I had HCV. Upon being told of this, I was just relieved that it wasn't cancer. We have a family history of cancer so this was my primary and overriding concern.

20. I didn't know what HCV was. Dr Foster was not a specialist so he knew very little. My daughter Sarah is a nurse and she did some research. I soon found out how serious HCV was.

21. I remember Dr Foster saying that he thought I had been infected through a blood transfusion. He believed that it was unlikely to be a result of the blood transfusion I had received in 1990 as it was too recent to be causing my liver function issue. He thought that it was more likely a result of the blood transfusion in 1975 during my hysterectomy operation.

22. Dr Foster referred me to Dr Paul, the consultant haematologist at Bassetlaw Hospital. Dr Paul wrote to Dr Bill Wagstaff (Sheffield Blood Transfusion Service) in a letter dated 22 August 1994 (**exhibit WITN6153002**). Within this letter Dr Paul describes my health issues and confirms that I received a blood transfusion on 06 June 1990. Dr Paul also identified the units of blood that were cross-matched at the Blood Transfusion Service.

23. In response, Dr James, consultant haematologist at Trent Blood Transfusion Service, wrote to Dr Paul in a letter dated 02 September 1994 (**exhibit WITN6153003**). Within this letter it was identified that the blood I had received in 1990 was prior to the routine testing of blood donations in September 1991 but went on to state "One of the donors whose blood she received was identified as HCV positive when they donated again after September 1991". This meant that it was most likely that I had been given contaminated blood during the most recent of my transfusions.

24. I had a liver biopsy at Bassetlaw Hospital on 13 September 1994. The results showed liver cirrhosis as a result of HCV infection, and confirmed that the HCV was still active. I knew what cirrhosis was and I was very shocked to hear this on top of the HCV.

25. Dr Corbett told me that there was nothing they could do. It felt like I had the sword of Damocles hanging over me. I just thought that was it and there was no cure.

26. Despite this my GP, Dr Foster, was brilliant. He knew about certain liver specialists in London GRO-C GRO-C He therefore decided to refer me to Dr C Tibbs at Kings College Hospital in December 1994.

27. Dr Tibbs was a specialist hepatology consultant with a particular interest in HCV. I believe he was undertaking a number of studies into the virus at the time. Dr Tibbs gave me a prognosis for the development of my

condition along with the grim realisation that I had around 5 years to live. He also said that, because the HCV was still active, I should be considered for interferon treatment.

28. I began to suffer considerable fear and anxiety as well as a feeling of isolation and bewilderment as I found that there were few people around me who understood the full implications of my illness and what I would be facing. This was life changing. I became extremely fearful about the future and began to suffer bouts of depression and acute anxiety.

29. I also felt a sense of anger that this could have been allowed to happen, particularly as I was aware that some people had also been inadvertently infected with HIV, due to transfusions with contaminated blood.

30. In September 1994 Mr Tibbs suggested that I begin interferon treatment. I began a trial course of interferon alpha medication in March 1995 under the care of Dr Corbett and Dr Paul at Bassetlaw Hospital. The treatment was a 12 month course that involved self-injecting interferon three times a week. I couldn't bring myself to self-inject the medication and, although he hated doing it, my husband Cyril did it for me.

31. The medication made me feel incredibly unwell, a lot worse than the symptoms of HCV itself. Beginning straight after the injection I had horrendous flu-like symptoms. After 6 months of persisting with the treatment, Dr Paul decided to discontinue the treatment because I had severe immunosuppression. The medication had also shown no signs of clearing the HCV infection.

32. Throughout this period, I suffered a number of debilitating symptoms and became very ill. I experienced acute pain and swelling. I also suffered with severe halitosis which was both embarrassing and inhibiting. I understood that this was caused by toxins seeping into my blood stream from my damaged liver. There were days that I was completely unable to get out of bed due to the severe fatigue. Even on my 'good days' I would still feel tired and need several hours of sleep in the afternoon.

33. I still tried to continue to work and on one occasion in 1994, I developed a sharp pain in my head and collapsed on my way in to work. I was admitted to Bassett Law Hospital, where it was determined that the pain in my head had been caused by the extreme pressure and anxiety resulting from the diagnosis of HCV and cirrhosis. I became very confused and my memory was poor. I felt dizzy and nauseous and I refused to go into town on my own. During this same general period, I also collapsed during a trip into town with my daughter.

34. As a result of my failing health and these incidents I was forced to retire. I had worked at the same store for sixteen years and had become the manager with a broad range of responsibilities. The shop had undergone considerable improvement in profitability in my time as manager and I had close friends among the staff. I was highly valued there and this was reflected in a personal letter from the Managing Director of the company upon my retirement.

35. I simply didn't have the energy or physical capacity to continue working. I loved my job, the people I worked with and my customers, so this was especially devastating for me. I had always planned my retirement to be when I reached 65.

36. Between 1995 and 1998, my health deteriorated rapidly. I was bloated, nauseous, had abdominal pain and diarrhoea, no appetite, memory loss, brain fog, a terrible temper and depression. My husband was forced to retire in 1995 to care for me on a full-time basis. We didn't know how long I had left at the time. The interferon treatment had failed and the prognosis was poor.

37. Over this period, I became a shadow of the person that I used to be. I had always been a fiercely independent woman but I lost this as my illness worsened. My husband took over for me and we both lost our respective roles in the marriage.

38. I continued to see Dr Foster once a month for blood tests and a check-up. Dr Foster was really good with me and always strived to ensure I got the best care available.

39. When I had gone to see Dr Corbett, he was adamant that I couldn't get a liver transplant. He didn't indicate why and gave no explanation, he just simply gave me 5 years to live, the implication being that I just had to get on with it.

40. Dr Foster was unhappy with Dr Corbett's decision and he decided to refer me to Dr Ryder, a consultant hepatologist at Queen's Medical Centre ("QMC"), Nottingham.

41. It was around this period that I first went to see a local solicitor Tony Hatfield of Jones & Co in Retford for legal advice. He worked very near to me and he used to say I didn't look well when he came into the shop. I felt that I needed someone to act on my behalf because I wasn't getting any treatment. I was then referred to a firm called Freeth Cartwright in Nottingham, as the local firm did not have capacity to deal with it.

42. I first saw Dr Ryder in December 1998 at QMC. Dr Ryder was fantastic; he had patients with liver problems and he specialised in hepatitis, so immediately he appreciated and understood the significance of my illness. Dr Ryder sent me to St James' Hospital in Leeds for an organ transplant assessment.

43. On 16 January 1999 I was admitted to the transplant unit at St James' Hospital where I was seen by Dr Miller. I told one of the junior doctors that I was struggling to swallow. They raised this with the senior doctor who decided to perform an endoscopy.

44. The endoscopy camera could only go so far because they found oesophageal varices that were significantly inflamed. There was a risk that the varices would rupture during this procedure. In fact, there was an ever present risk of rupture which could have caused a life threatening bleed.

45. I was diagnosed with portal hypertension. This was attributed to my HCV infection and the damage to my liver. I was very ill and my life expectancy was drastically reduced at this point.

46. After this, I was put on the waiting list for a liver transplant and I would be notified immediately, if a liver became available. I was given a pager which was to be activated by the hospital as soon as a suitable donor was found.

47. I had the pager with me at all times and experienced almost unbearable anxiety while we awaited a suitable donor. On one occasion the pager went off and raised my hopes, only to then find that it had been a false alarm. This was very stressful for all of us.

48. I had been told by the hospital that if a donor was found it was likely that I would be notified in the evening. Every time the phone rang during the evening, myself or my husband would pick up in the hope and anticipation that a donor had been found.

49. Living with these extremes of emotions on a day to day basis was very difficult.

50. On 28 February 1999, about two months after my transplant assessment, the pager sounded at 6am to alert me of a liver becoming available. I answered the call, there was a liver for me, it all felt quite surreal.

51. We got up and travelled to St James' Hospital in silence. When we arrived, the doctors prepared me for theatre immediately. I had no fears for the operation itself. I saw the transplant as an opportunity for a new lease of life and did not view it as a risky procedure. However, I had a irrational concern that the anaesthetic may not be effective and I'd wake up during the procedure.

52. At some point, the doctor said that he was doing a trial of anti-rejection drugs and asked if I would take part. I consented to this trial and was given a choice of two envelopes. I chose the envelope labelled tacrolimus, which was an anti-rejection drug being trialled at the time. Fortunately, tacrolimus was found to be effective and clinicians continued to use this, whereas the medication in the other envelope the name of which I cannot recall, was later found, I was informed, to have terrible side-effects and it was subsequently withdrawn.

53. I was taken down to the theatre at 9.30am for the liver transplant operation. When I woke up again in intensive care, there was a different surgeon in the ward. Dr Truegood explained that the other surgeon had been taken ill during the surgery and he had been called to replace him and complete the operation. As a result, I was in surgery for 1-2 hours longer than expected. That said, the operation itself had been a success.

54. However, the 'in hospital' recovery after the liver transplant was supposed to have been about 2 weeks. I ended up staying in hospital for 4 weeks owing to an infection. I recall being allowed out on Mothering Sunday and visiting a family friend's house. My family came around and said that I looked awful and I didn't speak all day.

55. When I returned to the hospital, I said to one of the nurses that I didn't feel well at all. Then, the wound from the liver transplant burst open from the swelling caused by an infection. I was put on an anti-biotic drip and taken to theatre for the infection to be cleaned out under anaesthetic and I was fitted with enormous stitches to hold it all together.

56. I was finally discharged 4 weeks after the liver transplant and I felt a lot better when I got home. I was able to think a lot more clearly. It was as if my mind had been cleared. Despite this, I still knew that I had HCV and that my new liver would begin to be attacked. I was told that there was a significant risk of developing cirrhosis in the new liver within five years.

57. I began a second course of treatment for my HCV infection under the care of Dr Ryder in 2004. This was an 18 month course that consisted of interferon injections once weekly and ribavirin tablets taken daily. As before, my husband had to inject the interferon into my stomach for me.

58. The side-effects of this treatment were dreadful. It was like having chemotherapy. The interferon completely wiped me out for 2 or 3 days. Then the effects began to wane and I used to look forward to the two days of feeling less unwell, before repeating the process with the interferon and it starting all over again.

59. I was closely monitored by Dr Ryder and the hepatology unit at QMC, attending the clinic on a Monday ever week for blood tests. My white blood cells were deteriorating sharply, in a similar fashion to the first treatment but not as badly. For the first 6 months the medication wasn't working but Dr Ryder said that I should stick with it another month.

60. After a month, the medication began to show signs of working. I persisted with the treatment in spite of the dreadful side-effects and, after 18 months, the HCV was 'undetectable'. Since completing the treatment in 2005/2006 the HCV has not returned.

61. I continue to have a check-up with Dr Ryder once a year. He is not obliged to continue treating me but he insists that I come to him for a check-up annually. I have had a number of liver biopsies since completing the treatment and these have all shown my liver to be fine. At my most recent check-up, my liver was fine and showed no scarring.

62. I was however also constantly worried that my body would reject my new liver at any time. I had to take the anti-rejection medication daily. The down side was that it had the side effect of suppressing and severely weakening my immune system. I was constantly worrying about catching an illness that would cause sickness or diarrhoea, which may in turn compromise the absorbency of the medication, which then led me back to the worry of the liver being rejected. I had to regularly check my body

temperature to detect any sign of developing an infection or organ rejection.

63. Recovery from just the liver transplant procedure itself, took at least three months. For approximately eight weeks I needed help with all areas of personal care and dressing.

Section 3. Other Infections

64. I did not receive any other infections as a result of receiving an infected blood transfusion.

Section 4. Consent

65. I did not explicitly consent to being tested for HCV in 1994, I simply consented to a general blood test for my liver function. I was not led to believe that this was for hepatitis. In hindsight, I also believe that I was probably tested for HIV/AIDS without my knowledge or consent.

66. I believe that I consented to all other testing and treatment that I received pertaining to my HCV and liver.

Section 5. Impact

67. The impact of contracting HCV, the damage to my liver, the effects of treatment, the liver transplant and then living with a transplanted liver, has had a monumental effect on me, my husband until his passing in 2019 and my family. I will in no particular order of the level of impact, try to relate what I/we have been through.

68. From a practical point of view the intensive nature of the transplanted liver medication, meant that I must ensure that I transported the required drugs when I was away from home for more than a few hours. This required considerable preparation and forethought but also presented practical difficulties in transporting and controlling potentially dangerous

substances. This remains to be the case today, though I do not take as many tablets as I used to.

69. The continued risk of infection caused by the suppression of my immune system meant that after the transplant, I was subjected to an extremely restricted diet. I had a tightly prescribed list of dietary requirements and had to be very careful not to consume foods which did not appear on the prescribed list. This in turn created problems with prepared food which meant that it was difficult to eat out in restaurants. I was rarely able to select from menus and usually had to ask the restaurant staff to prepare something that had been tailored to my requirements. This was very inconvenient and being unable to choose freely from the menu in the usual way was very frustrating. These dietary restrictions gradually disappeared over the years and I am now able to eat what I like.

70. My diet consisted strictly of low potassium foods and I was not allowed to eat fresh shellfish, pate, delicatessen products, sprouts, bananas or eggs, among numerous other items. Eggs gave rise to particular concern owing to the risk of salmonella infection. I was also forced to completely abstain from drinking alcohol owing to the active HCV.I have never drunk alcohol since.

71. Besides diet, other areas of my life have been profoundly affected by my illness and continuing risk of organ rejection. My husband, when he was alive, and I had always enjoyed travel and regularly went on holiday abroad twice a year with friends.

72. We would often travel to far away destinations such as Kenya, the United States and Bali. This then ceased, owing to a number of practical difficulties presented by my illness. For example, encountering problems arranging travel insurance on account of my liver transplant.

73. Regardless of this the constant threat of organ rejection and infection meant that from a psychological point of view I was very reluctant to

stray too far from doctors and hospitals who were familiar to me and fully acquainted with my medical history and condition.

74. I was also reluctant to travel to what might be termed exotic locations because the food is generally very different and I would struggle to explain my dietary requirements to restaurant staff, particularly where there is a language barrier to overcome.

75. Notwithstanding all of this, being both forced to give up work greatly affected our financial position and travelling abroad became a luxury which was difficult, if not impossible to afford.

76. Nobody can realise the impact of being told you are terminally ill unless they have faced it themselves. It is completely devastating, not only for the person involved but also their loved ones.

77. My anger associated with being diagnosed terminally ill is directed towards the blood transfusion service and the 'system'. I find that I am easily angered by those around me who claim to be ill, yet on my scale they would not even register.

78. The situation is still difficult to accept. I continue to ask many questions of myself, of others and of God. I tried to make bargains for more time, for better health. I felt much guilt and shame.

79. I sometimes felt depressed, that maybe I would have been better off dead, creating immense feelings of guilt and self-hate. I feel that I should be thankful for the life I have had and for the opportunity of extending my life through the transplant of a liver belonging to someone who had died before their time.

80. I feel guilty because I do not always feel thankful. I certainly do not feel worthy. Even now, although I have successfully survived a transplant, life is still an uncertainty. This has still reduced my life expectancy.

81. Long-term illness can have a large impact on a persons' self-image and self-esteem. Prior to my transplant, I gained weight and girth and as all areas of my life changed, I was no longer the same person. I was no longer a worker, a wife, a mum, a lover, a friend. I was just an ill person.

82. Self-image is affected by change in physical function, physical appearance, and the psychological impact of ill health. Poor self-image results in self-loathing and very low self-esteem. All this hugely affected those around me too.

83. Over time though, there has been a gradual improvement in the way I view myself and my self-esteem has also improved. Unfortunately, because of my illness I will never be the same person again and nothing can replace what I have lost.

84. Visually, I appeared to physically age at an accelerated rate within five years. I used to always look young for my age, but I then I appeared much older than my true years.

85. It is my opinion that I aged twenty years in the ten years between 1990 and 2000. This may be due to the fact that one of the functions of the liver is to regenerate cells, or possibly because of all the stresses and strains that illness has put on my life. Physically it was also difficult to hide my illness due to being jaundiced.

86. I loved my job and was extremely saddened when I had to retire through ill health. I am certain that if I had not had to retire early, then I would have worked there until my natural planned retirement at 65 years of age. I liked the personal interaction of my job so much; dealing with customers and working closely in a small team environment. I was never well enough to work again.

87. I used to enjoy gardening, walking, socialising, going on holidays and playing with my grandchildren. When I was very ill, lethargy made these pastimes either impossible or no longer enjoyable. I was unable to leave the country for one-year post transplant and was unable

to enjoy exotic holidays for years, because of the risk to my health. These were precious lost years, never to be regained.

88. I used to enjoy knitting but as my liver began to fail, I suffered from swollen, painful and stiff joints. This made knitting a hobby that I could no longer partake in.

89. As my illness progressed, breathlessness became an increasing problem. I had abdominal ascites that caused me to become unduly breathless after little exertion. I developed asthma and continue to take medication for this. My breathing improved post transplant but I still became breathless when climbing stairs for example. I still have problems with breathlessness but I now live in a bungalow and so stairs are not a constant problem.

90. Due to the dizziness and general weakness, during the worst period of my illness prior to my transplant, I was unable to go out and about on my own as I felt vulnerable and unsafe. The furthest I was able to walk unsupervised was to the end of our garden. Fortunately, the dizziness gradually improved following my liver transplant.

91. During treatment with Interferon - Alpha, I had to cope with many side effects. The most debilitating symptoms were that I permanently felt as though I had flu. Although the most dangerous side effect to my health was immunosuppression, this being the reason for discontinuation of treatment.

92. Unfortunately, this therapy has left me permanently immunosuppressed. Obviously, this could have had grave implications on any necessary future surgery, leaving me susceptible to infection.

93. As previously mentioned, immediately following my transplant, I contracted a wound infection that impaired healing, prolonged my stay in hospital and meant I had to endure the risks of further anaesthesia, as they put things right.

94. It used to be a constant worry that I may catch an illness such as diarrhoea and sickness, as this could reduce the effectiveness of the medication that I took so that my body would not reject my liver. I had to check my body temperature daily to help detect any sign of developing infection or organ rejection. This concern has subsided somewhat over the years but my children and grandchildren still worry about passing on such illnesses. This sometimes means that they have to restrict their visiting. During the Covid-19 pandemic this has presented added difficulties.

95. Liver disease caused problems with defecation as I would fluctuate from diarrhoea to constipation. My stools became very offensive and I would have been too embarrassed to defecate in a public convenience. It was even embarrassing to defecate at home because of the smell. Post transplant, I was left with an irritable bowel and I am still prone to constipation/diarrhoea.

96. Post transplant I developed hypertension and required regular blood pressure monitoring. This was not possible from March 2020 due to covid and has not really picked up again. That said, due to my diabetes I get it done that way.

97. I feel I am a resilient person and that I am strong in spirit. However, the pain I have suffered because of my ill health has on many occasions taken me to breaking point and made me feel as though I could longer cope with life.

98. It is difficult for loved ones to see someone they love deeply, suffering physical pain, and not being able to help. I think it is far more difficult for them to cope with their feelings of inadequacy when their loved one is suffering from mental anguish.

99. When I was first diagnosed with liver problems, it was a relief, as we had first feared cancer. This somehow amplified the torment when we discovered that I did have a terminal illness after all.

100. Viewing every day through fatigue compounded the symptoms from which I suffered. Every day I would wake up feeling tired, my body and joints would ache. I would have a gnawing pain in my side, I would feel nauseous, dizzy, my abdomen and ankles would swell with fluid.

101. As my liver disease progressed my whole body felt as though it was full of fluid, I felt uncomfortable and awkward and I had difficulty swallowing food. I would wake up every morning knowing that today would be the same, or worse than yesterday. This was soul destroying for me and my family.

102. After clearing the HCV, my health gradually improved. Most notable was my mind; I remember being able to think clearly and freely. I felt able to speak for myself again. This helped me to regain some control over my life.

103. Throughout my illness, the roles of my husband and mine had reversed. I had always been a strong-minded and independent woman but I lost this after my health deteriorated. My husband retired early and took care of me full-time. Having helped me for so long, he found it difficult to take a back seat again. It was a gradual transition but he struggled nevertheless, and he eventually became depressed. He was never able to come to terms with this. It was difficult for both of us and I knew I was treading on his toes. However, he was always caring and an affectionate, well-natured person.

104. Thankfully my husband and I were very close and we managed to work through it. It was a strong marriage and this enabled us to get over the humps. We were married for 56 years when he died in 2019.

105. Perhaps the most significant effect on my relationship with my family was that my medication caused me to become irritable, mildly aggressive and very intolerant. I was no longer able to take hormone replacement therapy, this appears to have exacerbated my low moods along with their frequency.

106. Prior to becoming ill, I was always a very outgoing and bubbly personality and I rarely allowed things to worry or upset me. When ill, I suffered long periods of anxiety, worry, frustration and anger. I am aware that the change in my personality has been particularly hard on my family, especially my late husband who had to live with its effects on a daily basis.

107. My long-term illness had a profound effect on all relationships. Long-term illness is similar to bereavement except that it can be more difficult to accept because there is no end, except the prospect of death.

108. All aspects of illness affect relationships with others. You begin to take on the 'sick' role. Discovering that you are terminally ill and that your life expectancy does not exceed ten years is obviously heart breaking. All the plans that as a couple we had made together, like watching our children and grandchildren grow and blossom. Following the transplant there was a huge uncertainty hanging over our lives. We did not know one day to the next what may happen. This is very difficult to live with. We lived and I still do, with the uncertainty of organ rejection and future illness.

109. My daughter GRO-C. I tried to encouraged her to slowly get back to work but I wasn't able to offer childcare for her children, GRO-C This was difficult for her and I found it very upsetting not being able to see and care for my grandchildren as much as I wanted to. I felt guilty.

110. I have always been very proud of my family. My daughter describes me as the matriarch of the family, the solid centre foundation that everyone looked toward. I lost this role with my HCV infection and illness. My crushing fatigues and general ill health prevented me being this 'figure'.

111. After my liver transplant and eventually clearing HCV, I used to fall out with my children. This was entirely out of character. Having been

forced to remain strong throughout the illness process, I had to process my emotions afterwards and come to terms with what had happened to me. I unfairly directed a lot of anger and frustration at my family as a result.

112. My liver is a constant concern. If I get a small pain, I instinctively worry that my liver is being rejected. This was especially bad in the beginning of my recovery, and also because of my immunosuppression. I am perpetually worried how long my liver will last. It has been 23 years since the transplant and I feel fortunate that it has lasted this long. This is always in the back of my mind.

113. My HCV also had an effect on the way that I approached meeting new people and forming relationships with them. Whereas I was previously extremely outgoing, I became wary of people's perceptions of me and their reactions towards my illness. I discovered that if I mentioned the word "hepatitis" to people their automatic reaction was to assume that I was contagious.

114. People knew or know very little of Hepatitis C and this ignorance incites fear. An example of this arose in September 1995 when my husband Cyril and I went to Majorca on holiday. We became friendly with a couple from Scotland who were themselves on holiday with some friends. On a particular day, all 6 of us arranged to meet on the beach. When we arrived, one of the party, who was called GRO-C was missing. When I enquired as to why he had not arrived I was informed that GRO-C had decided not to come because he did not want to catch Hepatitis C.

115. A similar incident occurred in 1994 when my sister-in-law discovered that I was ill and mistook my condition for HIV. Over the years I have found this to be a common misconception. My sister-in-law approached me while I was at work in the shop and asked me why I was working and putting my customers at risk. Her frankness at least enabled me to explain the reality of the situation to her.

116. Another incident occurred in 1999 when my son formed a relationship with a young woman whose family advised her "not to get involved with the Lindleys because they had hepatitis in their family". These incidents caused me considerable humiliation and left me wondering how many other people have misconceptions about my illness or mistook it for HIV.

117. Prior to my transplant I became very jaundiced and I even experienced people insinuating that this was due to working amongst wine and spirits and having too much of a liking for them. The only reaction I have had to people's ignorance was to laugh at it and try to refute what they believed, as I was always concerned that people would repeat their misplaced fears to others. The comments invariably caused me considerable hurt under the surface. I tried hard not to display this.

118. As I have previously alluded to, my illness caused me to age at an accelerated rate which in turn affected my self-confidence. Prior to the transplant I gained a lot of weight and suffered 40% hair loss. After the transplant, I gained a greater incentive to look after my appearance.

119. However, certain things continued to have a negative effect on my self image, such as the prominent scar tissue across my torso. I find this rather embarrassing and have not liked getting undressed in front of other people. This meant that I was/am very reluctant to go swimming, an activity which I had always enjoyed.

120. Even after my 'new' liver was functioning normally, I continued to experience extreme tiredness and found difficulty sleeping which in turn compounded the fatigue. I had had to accept that I would never be able to return to work. The feelings of depression which I experienced after retiring from work, alleviated to a degree over time but I still missed my colleagues and the daily challenges presented by an active working life.

121. After contracting Hepatitis C there was a considerable deterioration in my vision. I was advised to have an annual visual

acuity test and the rate of deterioration was such that I had to incur the cost of new bifocal spectacles following each test. In December 1999 I underwent laser therapy for acute glaucoma. I understood that the deterioration in my eyesight may have been caused by my anti-rejection medication. Again, these appointments have not picked up again since the covid pandemic began.

122. During my illness, having both given up work, our finances naturally dropped quite severely. We had to spend money from savings and sell what shares we had in order to maintain a reasonable standard of life. In addition, I had to pay out for transport costs for the many hospital visits, medical expenses such as prescriptions. I also had to buy special clothing to accommodate my increased girth, weight and scar tissue.

123. After my HCV diagnosis, my wider family were terrified of sharing cups or cutlery with me. Some people didn't want to visit me as a result of fear and ignorance. My daughter who is a nurse, was always very mindful and rightly so, that I was careful with cuts and bleeds.

124. My energy levels and mental capacity improved dramatically after the liver transplant. Once I got over the initial stage of worrying about infections being brought into the house, I began to feel much happier. I regained my appetite and I was more like my old self.

125. I have been diagnosed with diabetes type II, which was attributed to my liver transplant. I was also found to have bronchiectasis after the transplant, which has developed into chronic obstructive pulmonary disease (COPD). I believe this was caused by the trauma to my body resulting from the transplant. I regularly use a steroid inhaler in relation to this.

126. I suffer from skin cancer. I have been told by medics that this is a side effect of the anti-rejection medication that I take. I have had 4

melanomas removed and I am currently waiting on results for two other suspicious growths.

127. I had been a blood donor until 1985. My husband was a regular blood donor and had gained a silver medal for his contributions. However, he was no longer allowed to give blood after my HCV diagnosis, being the husband of an HCV positive person. This deeply upset him and he felt it was unjustified and discriminatory.

128. I was advised, I cannot recall by whom, that my husband and I should practice safe sex. My husband didn't agree with this and said that he would risk it. He would say that if he got HCV, then he got it.

129. I had been denied normal travel and holiday insurance since my HCV diagnosis and transplanted liver. However, I managed to get cover by opening a Gold account with my bank. The insurance comes with the account and they don't ask questions, although they do know my medical history now. This stops when I turn 80.

130. I have already touched on the effect of my illness upon my/our financial situation. Quite apart from the sadness I feel at being forced to retire from my job, we went from being financially comfortable to having little money for luxuries. While I was working, I had the benefit of a bonus scheme based on sales, which enabled me to earn extra money which could be considerable. I remember that my first bonus paid for a holiday to the USA. I also have an occupational pension which has of course been diminished in value by my enforced early retirement and the cessation of contributions from my earnings. Cyril was also forced to take early retirement from his job to look after me. Continuing financial worries compounded my anxiety about my illness and my fears for the future.

131. During my ill health, I found it difficult to attend church and related events and functions, something that was and still is a very important part of my life. This caused feelings of guilt and self-directed anger.

Legal claim

132. At some point, roughly around 1997 or 1998, Freeth & Cartwright solicitors started to pursue a class action against the National Blood Transfusion Service ("NBTS") under the Consumer Goods Act 1979. It seemed a strange way of fighting the authorities for what they had done but the lawyers found that this was a way that success could be achieved. The government had failed to acknowledge any wrongdoing, so how else were we meant to get the proper redress?

133. I was chosen as the lead case in the class action. I believe I was chosen because I could prove, categorically and beyond any doubt, that I was infected through a blood transfusion in 1990 at a time when a test was available for the detection of HCV in blood samples and the NTBS had elected not to test until the following year. My circumstances are evidenced earlier in this statement in exhibits **WITN6153002** and **WITN6153003**.

134. There were 3 'lead' cases, including myself. In total I believe there were 190 litigants, although I cannot recall if they had the same or similar evidence as I had. I am well aware that I was fortunate to have records of the blood units I received in 1990.

135. I subsequently learned from Dr Paul that the donor who infected me must also have contracted HIV as well as HCV. He explained that this donor later infected another patient who became infected with both HIV and HCV after receiving a blood transfusion. I believe the donor was an American prisoner.

136. The class action claim was heard at the Royal Courts of Justice in 2000. The case, against the NBTS, lasted for 5 days. I was on the stand for 2 of the days as the 'lead' case chosen by the claimants. My daughter Sarah and my husband also gave evidence. Dr Ryder attended and gave evidence. I recall having to have a psychological assessment prior to the hearing.

137. The defence tried to argue that I wouldn't have worked until I was 65 years old, having retired due to ill health at 50. However, my employer provided a statement that rejected this, stating that I was a great employee who was sorely missed and they would have expected me to work there for as long as I could.

138. One point of contention in the hearing was the fact that I developed cirrhosis of the liver just 4 years after becoming infected with HCV. This, the defence argued, suggested that I was infected much before 1990, possibly in 1977 during the hysterectomy operation when I also received a blood transfusion.

139. However, our legal team had conducted extensive medical research and found evidence that showed the cholecystectomy operation, to remove my gall bladder, in 1991 had accelerated the effects of the HCV and thus precipitated the damage found. In terms of me being given imported contaminated blood; my HCV genotype was apparently extremely rare in the UK and so strongly suggested that the blood I received had been imported.

140. The judge clearly took an interest in this matter and the next day, after this evidence had been heard, came to court and issued a statement. He read from the medical journals he had researched the previous evening and all his evidence was fully referenced. The judge concluded that it was entirely possible for the extensive cirrhosis and damage to my liver to have been caused within 4 years owing to my HCV genotype and the cholecystectomy operation performed in 1991. He was satisfied with this and rejected the defence's argument.

141. I won the case and was awarded £250,000 plus legal costs. I believe the damages I received were high mainly because of the loss of earnings element of my claim.

142. As an aside, I remember around the same time that the GRO-C brothers were in court and were in receipt of legal aid. I received no legal aid whatsoever, which is utterly unjust.

143. My daughter Sarah and my late husband Cyril, made their own impact statements about how my illness affected them. I would like the inquiry to be aware of these and so I exhibit them as **WITN6153004** for Sarah's and **WITN6153005** for Cyril's.

Section 6. Treatment/Care/Support

144. I noticed that doctors and nurses wore considerable PPE, whenever I had a liver biopsy. My medical files always had a yellow sticker on that said 'infectious' or 'infectious blood'. I didn't like this, I felt ostracised.

145. I have never been offered any counselling or psychological support by the NHS as a result of being infected by contaminated blood, as described.

Section 7. Financial Assistance

146. My solicitor phoned me when the Skipton Fund was first established and said that I could apply although I had to do it myself. I completed the form with my solicitor talking me through it.

147. I sent my application with the support of Dr Ryder and it was accepted straightaway. I think that I received two lump sum payments of £25,000 each.

148. I receive a quarterly payment of £7,000 from the English Infected Blood Support Scheme, totalling approximately £28,000 per annum. I also receive a winter heating allowance of around £500.

Section 8. Other Issues

149. The effect of Hepatitis C on my life has been devastating. It is extremely difficult to convey to anyone the impact of being terminally ill and facing death. In addition to the fear and trauma I have experienced, I have considerable anger towards the blood transfusion service and the health authorities.

150. The situation remains difficult to accept and I find that I sometimes try to deny what has happened. The bitterness and resentment that I feel in turn cause feelings of guilt and shame because I feel that I ought to be grateful for the life that I have had and for the opportunity to extend my life through the transplant.

151. The support and love of my family has been invaluable in helping me to confront my illness and their support remains vital to me, living day to day with the constant threat of organ rejection and further liver failure.

152. This infected blood situation should never have happened in the first place. The government knew about this. I have never received an apology. This angers me more than anything.

153. I had to fight to get compensation. HCV took my previous life away and I 'lost' years, yet I feel incredibly lucky that I have survived. But this isn't the life that I would and should have lived.

154. No one has taken responsibility for this. The fact that the legal case that I was a part of had to brought under the Consumer Goods Act is staggering. There should have been a better source of redress for those affected by this tragedy.

Statement of Truth

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

Signed GRO-C

Dated 20-4-2022