Witness Name: GRO-B
Statement No.: WITN7271001
Exhibits: **WITN7271002 - 004**
Dated: 17 November 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

ANONYMOUS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 04 October 2022.

I GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1947 and my address is GRO-B London GRO-B

2. I live with my partner GRO-B We are both retired. I was previously married. My ex-husband and I were married for GRO-B years and divorced in 1993, although we remain friends. We have two daughters, GRO-B aged 52 and 43 respectively.

3. I intend to speak about my infection with hepatitis C ("HCV") following a number of plasmapheresis procedures in 1979. In particular, the nature of my illness, how the illness affected me, how I spontaneously cleared the infection and the impact this all had on me, my family and our lives together. I will also speak of other procedures that I had involving blood transfusions.

4. The anonymity process has been explained to me. I wish to have anonymity.

Section 2. How Infected

5. In [redacted] 1968, I was 12 weeks pregnant when I suffered a miscarriage. I was taken to St Stephen's Hospital on Fulham Road (now the Chelsea and Westminster Hospital), London, where I had a 'D&C' (dilation and curettage) procedure.

6. Around a month after this, I was staying at a friend's house in [redacted] I had a bath one evening and, when I stood up, I saw huge blood clots coming out of me. The image was horrific.

7. I couldn't let my friend see this so I tried to pick the blood clots out from the bath and flush them down the toilet. It was horrendous, I would describe it as a huge haemorrhage.

8. My friend phoned her local GP who said I could go up to the practice and see him. This GP saw me and said I should go home to [redacted] so that I could be admitted to St Stephen's Hospital rather than the cottage hospital close to my friend's house.

9. I did so and I was subsequently admitted to St Stephen's Hospital (now rebuilt as The Chelsea & Westminster Hospital) in the Fulham Rd. I had a saline drip fitted immediately. The doctors told me I needed surgery but my haemoglobin levels were too low. This meant that I needed a blood transfusion before they could operate on me.

10. At this point I was told that I had a rare blood group, which I later learned to be O rhesus negative and they had no immediate supplies with which to administer to me. They were phoning around other hospitals to locate some of my particular blood type, which probably took an hour or two before it arrived and was given to me.

11. I was aged 21 at this time and did not think to enquire what my blood group was and no one explained the serious implications of my blood type and its impact on pregnancy.

12. I became pregnant again in 1970. I was under the care of GRO-B GRO-B Maternity Hospital in GRO-B where I was working as a secretary in the Social Work Department. It was at GRO-B where I was first informed that my blood type was O Rhesus Negative.

13. My husband's blood was also tested and he was A-Positive, which was incompatible with mine. They also established that I had developed high Rhesus antibodies.

14. I went into labour at 34 weeks and gave birth to my eldest daughter, GRO-B She was immediately taken to the special care baby unit ("SCBU") where she received a complete blood exchange procedure. GRO-B was severely jaundiced at birth, which was anticipated owing to my husband's blood being incompatible with mine. However, she soon got better after the blood exchange and went on to be a healthy child.

15. In 1971, I was pregnant again, with an extremely high Rhesus antibody level. At this stage I had returned to work at GRO-B Hospital, but was now working in the Haematology Laboratory as a secretary to the haematologists and pathologists. The senior haematologist, who I believe was called either GRO-B spoke to me about my pregnancy, conscious of my previous problems and told me that I would receive his best care and attention.

16. At roughly 16 weeks gestation, I began a series of intrauterine transfusions. This procedure entailed the foetus being given blood transfusions via a needle through my abdomen. After the fourth procedure, I went into labour at 34 weeks.

17. I gave birth to GRO-B who weighed only 4.5lbs and was extremely ill and noticeably jaundiced. She was rushed to the SCBU where she received approximately eight blood exchanges. However, she developed necrotising enterocolitis and was transferred to Great Ormond Street Hospital where, after undergoing abdominal surgery, she very sadly and tragically died at 11 days old.

18. GRO-B later apologised to me because he had 'missed' a change in the range of antibodies and had therefore been giving the baby the wrong type of blood in the intrauterine transfusions. He said he was deeply sorry and should have been 'looking out for them'.

19. One of the members of staff at GRO-B told me I could sue for this mistake but I didn't want to bring a legal case, in part because I didn't have the strength to go through with the process but mainly because it wouldn't bring her back, and no amount of money could compensate for this. I had received a heartfelt apology and that was that.

20. My husband and I had come to terms with not having any more children. We were deeply saddened by this and felt our daughter was missing out on having a sibling. I regularly attended a family planning clinic and at one of these meetings I met Dame Josephine Barnes who, after listening to my history, told me that a close friend of hers, a haematologist, was running a programme at Lewisham Hospital working with mothers who had Rhesus antibodies.

21. Dame Josephine Barnes referred me to this haematologist, a male whose name I cannot recall although I believe his first name was Cecil. I went to meet Dr 'Cecil' and he explained how it would work. I would attend his clinic at 16 weeks gestation, they would extract a pint of blood,

'spin' the blood to separate the red blood cells from the plasma, then they would return the red blood cells to me but I would then receive donated plasma. Dr Cecil said the primary risk to me was the loss of all my antibodies, not just the Rhesus antibodies, which would compromise my immune system. I had assumed this meant I would get more colds and flu than most people.

22. One other risk would be the amniocentesis procedure that I would have every week to monitor the Rhesus antibody levels. This procedure involved a large needle attached to a syringe withdrawing amniotic fluid from my abdomen, which would risk triggering a miscarriage. The odds of success were officially 50% but I believed it to be higher than that unofficially. My husband and I discussed this and decided to proceed with the programme. I was also told that my plasma would be used to make Anti-D to be given to mothers who had my O Rhesus Negative blood type as soon as they gave birth.

23. I duly attended the clinic at Lewisham Hospital at 16 weeks gestation to begin the plasmapheresis therapy. I attended the clinic for plasmapheresis transfusions twice a week for a total of 18 weeks. I remember vividly the plasma came in varying shades of yellow and was administered to me from a clear plastic bag. I distinctly recall having a chat with the one of the doctors one day and I asked "where does this [the plasma] come from then?". The doctor said that it was imported from the United States.

24. Around GRO-B 1979, two weeks before I gave birth, I developed terribly itchy feet like I had never experienced. The itching was so unbearable that I scratched my feet until the skin broke. When I told the doctors about this, I remember them sharing a long, knowing look at one another. They then went away and came back with a different plasma that was contained in a bottle, not the floppy plastic bag that I had become accustomed to.

25. The doctors said they were giving me a different plasma "…..to be on the safe side". They said it was 'filtered' and called 'exhausted plasma', which I remember made me smile at the time. This bottled plasma was paler and clearer than the plasma from the bag that I had been given for 16 weeks, from week 16 of my pregnancy. I only had this for the last 2 weeks and so only 3 or 4 times.

26. On GRO-B 1979 I received a phone call from the hospital asking that I come in to be induced because my Rhesus antibody count had become dangerous for the baby. I gave birth to GRO-B the next day, on GRO-B 1979, and she weighed 6lbs. Like GRO-B was urgently transferred to the SCBU where she received 'light treatment', her eyes were protected by a mask, and she was fed expressed breast milk through a tube. Her blood was exchanged twice and she stabilised. Aside from a heart murmur and 'head lag' that resolved in a few months' time GRO-B went on to be a healthy child, apart from severe eczema.

27. I was extremely exhausted on the ward and obviously highly anxious about my baby. I spent hours up in the SCBU so I missed the doctors' rounds on the ward, so no one seemed to notice that my appearance was yellow, least of all myself.

28. Only afte GRO-B had stabilised and I was discharged did I notice I was jaundiced. I felt awful, extremely fatigued and nauseous, and also had pale stools and dark urine. I went to see my GP, Dr Andrew Bailey.

29. Dr Bailey had a colleague in the room with him. As I explained these symptoms, the two doctors shared another long, knowing look just as they had done in Lewisham Hospital when I complained of itchy feet. Dr Bailey said I needed a blood test at once and I should contact Lewisham Hospital.

30. It was at Lewisham Hospital that I was told I had hepatitis. I can't remember whether they said I had hepatitis A or B but they did tell me they were tracking down the plasma that I had donated over the 18 week

course of plasmapheresis procedures. This plasma had been used to make Anti-D for O Rhesus Negative mothers and they weren't sure they had found it all, which was a very disturbing thought for me.

31. Dr Bailey told me there was no treatment for hepatitis. He advised me to rest and eat a fat-free diet and abstain from alcohol for 6 months. Dr Bailey undertook enquiries with a liver expert, which didn't seem to provide many answers.

32. I asked Dr Bailey if I could continue to breastfeed. He said I should "go with [my] motherly instincts" and that there was no concrete evidence it would be harmful to the baby. I decided to stop breastfeeding as a result of this conversation. I was going by my 'motherly instinct', as advised.

33. In the period between 1979 and 2014, with the benefit of hindsight, I was suffering with constant fatigue and persistent brain fog. This also compounded the other medical issues I was having as a result of a genetic heart condition.

34. In mid-February 2014, I went into Oxford for the day with my daughter. We were outside in the freezing cold and when I got back to her house I seemed to have developed a chest infection. I was coughing all night and I coughed up blood.

35. At that time, I was prescribed and took a prophylactic dose of antibodies every day owing to the immunosuppression that resulted from the plasmapheresis procedures in 1979. I had been a smoker for a long number of years but had quit in the two weeks prior to developing the chest 'infection'.

36. My GP referred me to Dr Bowen, a chest doctor, at Charing Cross Hospital. I had all kinds of scans and Dr Bowen said she didn't think I had cancer. She identified that I had fluid in the pleura of my right lung. Dr Bowen gave me all sorts of different antibiotics but none of these were working. I was also getting regular UTIs (urinary tract infections).

37. After several weeks, I was admitted to Charing Cross Hospital in early May 2014. I had blood tests in connection with my chest problem. The doctors came to see me on the ward rounds and asked me if I had ever had HCV. I said not to my knowledge, but I think I had hepatitis A or B in 1979.

38. The doctors explained that I had tested positive for HCV antibodies. They said they needed to do another test to determine whether it was still active or not. They said that HCV hadn't been discovered until the 1980s so I was probably misdiagnosed in 1979. I was then referred to Dr Dhar, the consultant hepatologist at St Mary's Hospital, Paddington.

39. When I first saw Dr Dhar, he was of the opinion that my HCV was on the mend. I went home but two days later I received a phone call from Dr Dhar informing me that my test results weren't good. He asked me if I looked yellow. I ran to the mirror and said I wasn't sure, but I could be. He said I should 'have a think' and then phone him back.

40. My daughter came round after this phone call and said I looked terrible. She later told me my speech was slurred. I phoned Dr Dhar back; he said he didn't have a bed for me at St Mary's but I should go directly to Charing Cross Hospital A&E and get admitted there.

41. I was admitted to Charing Cross Hospital via A&E and the next day (my birthday, GRO-B 2014), I was transferred by ambulance to St Mary's Hospital. My blood test results had arrived and I remember Dr Dhar telling me one particular reading was very high, but I can't remember exactly what this was for.

42. At this time my skin was orange. My daughter later told me that I was exhibiting abnormal behaviour, which the doctors told them was caused by toxins in the brain resulting from liver failure.

43. I was put on a ward with a lot of alcoholics. They would start fights with staff at night and bang on the doors and windows. The conditions in the ward were horrible. The men's toilet would often block so the men would

use the women's facilities and it became filthy, which was intolerable for me as I had frequent bouts of diarrhoea. There was one elderly patient on the ward with dementia who screamed all day and night and there was a patient that had about nine visitors when it should have only been one or two.

44. I tried to discharged myself one night, I was just finding it unbearable. The doctor in charge of the ward at the time persuaded to me to stay. She said I was borderline for a liver transplant, which just showed how ill I was.

45. I underwent a liver biopsy whilst at St Mary's Hospital. The doctor who performed it said they would ordinarily go through my side to reach my liver, but they had a new method that went through a vein in my neck, which may have been the jugular vein.

46. The liver biopsy lasted over an hour and I was in excruciating pain throughout. The doctor couldn't get the needle to penetrate the surface of my liver, and each time he tried it caused agonising pain in my shoulder. I felt like I was on a rack in the Tower of London. He finally extracted one drop of fluid and said he had never encountered such a tough liver before.

47. At some point whilst admitted to St Mary's Hospital, I also had a liver ultrasound. The results of this were unremarkable and the liver seemingly didn't appear to be too bad. I recall the radiologist said something about 'night sky and stars', which I believe was how they described the appearance of my liver condition on the scan.

48. Dr Dhar told me that I had definitely had HCV, most likely from the plasmapheresis in 1979, and that I had the antibodies to show it. The HCV was no longer active but he wanted to keep an eye on my liver function. He said I was one of the 20% of HCV positive patients to have spontaneously cleared the infection. I was never offered treatment because my HCV wasn't active when discovered.

49. Dr Dhar explained that my liver had been compromised by the HCV, which was exacerbated by the multitude of antibiotics I was prescribed in the build-up to May 2014. He said that my GP should continue to take blood tests from me every 6 months, presumably to monitor the HCV and ensure it doesn't reoccur. My blood tests have been fine since being discharged from St Mary's Hospital on 29 May 2014. However, the HCV has damaged my liver along with medication I had been taking over a prolonged period and I was told that I was more prone to developing cirrhosis or liver cancer as a result.

Section 3. Other Infections

50. I don't believe I suffered any other infections from the transfusions administered to me.

Section 4. Consent

51. I don't believe that I have been tested or treated without my consent. I was not explicitly informed that I was being tested for HCV, but this does not concern me because it led to my diagnosis.

52. I believe Lewisham Hospital wanted to keep me in the dark about the possibility of me contracting HCV or whatever it was called then, from the plasma administered to me in 1979.

Section 5. Impact

53. My family had reconciled themselves to me dying. It was extremely traumatic for my family to see me in such ill-health. It was equally traumatic for me, which was made worse by the conditions of the ward at St Mary's Hospital.

54. I have suffered with a number of health problems throughout my life. I believe some of these to have been exacerbated by my HCV infection. I have developed age-related wet macular degeneration in my eyes, which requires injections every two months.

55. I also have regular recurrences of purple spots flaring up on my chest, arms and back. These look like a purple felt-tip pen has been used to draw spots all over me. I believe this to be a result of HCV infection. I also continue to suffer with brain fog and memory loss.

56. When I was first diagnosed with hepatitis in 1979, both my GP and Lewisham Hospital indicated this was nothing to worry about. I was advised not to kiss my children and that hepatitis could be passed on through fluids. However, liver damage and disease were never mentioned until I met Dr Dhar in 2014.

57. I think on the whole my husband and I disregarded this advice. We were both exhausted and had a lot to deal with alongside our long-term medical conditions. I remember mentioning hepatitis to a neighbour when she asked about the new baby. I said this very casually, simply because I didn't believe my diagnosis to be of any significance whatsoever. No one told me it could be very serious and lead to chronic liver disease.

58. Whilst on the ward at St Mary's Hospital, some people would assume I was there because of alcoholism. This was almost a default assumption amongst people. I never knew intravenous drug users were associated with HCV. I tried to shrug off these judgements about me because I knew the truth. I found it best not to mention HCV to others, except to dentists and other medical professionals.

59. I was told to inform dentists about my HCV infection. In 1979, I was advised to wait six months before having dental treatment. When I did see a dentist, I noticed they wore extra protection, which is understandable. I suspect they too were under the impression that it was

hepatitis A or B that I had, otherwise what did the 'wait six months' mean?

60. My long-term and constant fatigue meant I wasn't able to work as much as I would have liked. My husband was also unwell, which meant he couldn't cope with the physical demands of his job. This put us under a lot of financial strain, at a time when we were trying to raise our children and pay the mortgage.

61. My youngest daughter is currently waiting for a PCR test to determine whether she is also infected with HCV. She has had health issues all her life and I carried her while infected with what we now believe was HCV.

Section 6. Treatment/Care/Support

62. I have not faced any difficulties in obtaining treatment, care or support in consequence of my HCV infection. That said it was maybe not diagnosed when it should have been.

63. My chest doctor found it difficult to diagnose my lung problem because of my HCV infection. She wondered if it was a complication of the liver damage.

64. I have never been offered any counselling or psychological support.

Section 7. Financial Assistance

65. I have never asked for financial support and never looked for it. Before contacting the Inquiry, I wasn't aware of the existence of any financial support schemes.

66. The Inquiry investigator has informed me of the existence of the English Infected Blood Support Scheme ("EIBSS"). I intend to discuss the possibility of applying to EIBSS with my daughters.

67. I saw in the news that the government were going to give £100,000 to those affected by contaminated blood. It was the news of this and a conversation with someone at the HEP C Trust, that highlighted the Inquiry to my daughters who urged me to make contact with the inquiry.

Section 8. Other Issues

68. I have a number of documents encompassing correspondence confirming my diagnosis with HCV in 2014. I enclose as exhibit **WITN7271002** a letter dated 19 October 2020 which reads: 'Prior hepatitis C exposure after plasma-phoresis [sic] during pregnancy in the 1970's' and 'History of drug induced hepatitis secondary to antibiotics'.

69. I enclose as exhibit **WITN7271003** a letter dated 10 August 2015 which shows my HCV antibody positive and HCV PCR negative results from 07 May 2014. I also enclose as exhibit **WITN7271004** my discharge summary, showing my previous medical history and most pertinently that I 'spontaneously cleared hepatitis C'.

70. Lewisham Hospital have informed me that my records from 1979 have been destroyed. I also note, from their website, that they seem to have abandoned the plasmapheresis procedure for pregnant women. I have also been informed that my GP records relating to 1979 are unobtainable. I asked if they have been destroyed and the receptionist just replied "probably'.

71. I feel compelled to add that had I been given the Anti-D injection at St Stephen's Hospital after the miscarriage in 1968, I wouldn't have had the Rhesus Negative antibody problem, which means I wouldn't have needed the plasmapheresis treatment at Lewisham Hospital which led to my HCV infection.

72. I was urged to contact the Inquiry by my eldest daughter, who felt my story should be told.

Statement of Truth

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

Signed **GRO-B**

Dated 17th November 2022.