Witness Name: GRO-B
Statement No: WITN7324001
Exhibits: **WITN7324002 – 03**
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 October 2022.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My full name is GRO-B I was born GRO-B 1947 and my address is known to the Inquiry. I have been married to my husband GRO-B since GRO-B I am a retired secretary/pa and I worked until I was 61 years old, my husband is a retired joiner and Builder.

2. We have two daughters, my first daughter was born in 1976 and has been residing in the USA for the last 17 years. My second daughter was born in 1979 and has been residing in New Zealand for the last 16 years.

3. I wish to talk about my infection with Hepatitis B (HBV) and Hepatitis D (HDV) as a result of receiving infected blood through a blood transfusion in 1977.

4. I confirm that I am currently not represented and I am happy for the Inquiry to assist me with my statement.

5. I also confirm that I have been given the option to remain anonymous which I have taken.

6. The right to reply process has also been explained to me and I understand that anyone that I may criticise in my statement has the right to respond to the criticisms made.

Section 2. How Infected

7. In October 1977 between the births of my two daughters I had a miscarriage. I was admitted to Harrogate Hospital for a D&C and discharged the next day. Over the next few days things did not settle down and I was losing a lot of blood. My GP Dr GRO-B prescribed Ergometrin but this did not have any effect.

8. Eventually we had to call the doctor, Dr GRO-B (now deceased) came out in the evening as I was losing blood, there were clots as big as a fist. The doctor was reluctant to make the visit as he was at a dinner party, despite being on call. When he did arrive he immediately ordered an ambulance and I was transported to Harrogate Hospital.

9. At the hospital they decided that I had lost so much blood that I needed another D&C and, very late at night, around midnight they opened up the operating theatre and performed the procedure. A Sister at the hospital described the procedure to me the next day and explained what had gone wrong.

10. Apparently, the womb had not been evacuated properly and therefore I was still haemorrhaging, I had lost lots of blood and needed a transfusion which they administered. I was not given the choice as far as I can remember, but I relied on the Professionals to give me advice, so I probably would have said yes to the procedure anyway.

11. It took quite a while for me to get pregnant again and my second daughter was born in GRO-B 1979

12. I believe it is most likely that I was infected with hepatitis B through the blood transfusion. I do not have body piercings, or tattoos, I don't even have my ears pierced. I have never taken drugs or used needles.

13. On 4th June 1999 my eldest daughter persuaded me to give blood at the local blood donor centre, which was visiting GRO-B I did not think that I could give blood as I had had a blood transfusion in 1977 however it seems that the rules had changed and I was allowed to donate.

14. I gave the blood but then on the 28th of June 1999 I received a letter from Dr GRO-B from the blood donor HQ at GRO-B in Leeds that they could not accept the product as it was infected with hepatitis B. This letter is produced as exhibit **WITN7324002**

15. I was called to an interview with Dr GRO-B in Leeds on the 2nd July 1999 and spent quite a while answering very detailed and personal questions about my health, social and sexual activities. The doctor asked about various other aspects of my life to try and ascertain where I could have been infected.

16. I advised her of our overland trip from Australia to the UK and explained that we had driven back through Sri Lanka, India, Pakistan, Afghanistan, Iran, Turkey and then through Europe. I had been in good health throughout this trip. I also told her about the miscarriage and the botched D&C resulting in a blood transfusion in 1977. Dr GRO-B then took another blood test to confirm the Hep B findings and I gave her permission to see my records at Harrogate Hospital.

17. On the 16th of July 1999 blood results came back as positive for Hepatitis B and my liver function was slightly abnormal.

18. My husband had to give a blood sample to rule him out as being a carrier and my daughter's both gave samples to confirm that they had not been infected in any way.

19. I was then referred to the hepatology department at St. James' Hospital in Leeds. I got an appointment at St. James' on 28th July. During this appointment we again went through everything I had told Dr GRO-B and the doctor examined me and said my liver looked enlarged and then arranged for a biopsy on the 2nd September.

20. I was worried about this delay and phoned Dr GRO-B who got the appointment changed to the 12th of August. On the 9th of August the hospital phoned and said they could not go ahead with the biopsy as the blood test results were not back. This appointment was rearranged for 26th August. On the 25th August I had to go to Leeds hospital for more blood tests before they could do the biopsy.

21. On the 26th of August after I had a scan, the biopsy was performed. I had to lay on my back for 6 hours while this happened. It was excruciatingly painful.

22. On the 10th of September I received the results. There was scarring on my liver with cirrhosis and therefore I would not be able to have the Interferon treatment as this could make it worse. They were not sure how long the damage had been done, so they needed to keep an eye on me, to be monitored periodically with a biopsy probably every 2 years. They made an appointment for a scan in 3 month's time.

23. On the 28th October I had an MRI scan, I spent nearly 4 hours at the hospital. On the 23rd of December I had an ultrasound scan and more blood tests. The results from the MRI scan showed two large nodules on the Liver but they did not appear to be cancerous. There were also some changes on the ultrasound from the scan I had previously.

24. I had many scans, went for blood tests and attended many consultations over the next few years. I attended clinics approximately every 3 to 6 months. These clinics were a nightmare. We were sat in the waiting room with drug addicts, prisoners that were handcuffed to prison officers and the like. The prisoners were shouting across to each

other "what you in for". This was a very intimidating and upsetting experience.

25. I believe the department could have made more effort to segregate patients as this caused stress and anxiety not just to me but to other patients.

26. Throughout this experience I enjoyed reasonable health and was quite active. My husband and I enjoyed walking however, I could no longer walk as far as I used to. The fact that I had this infection was always on my mind, it was like carrying a huge burden around with me, not knowing how the disease would progress left me anxious.

27. Over Christmas in 2005 I noticed a swelling in my abdomen which gradually got worse, in fact I looked 8 months pregnant. I did have an appointment in early January 2006 but I telephoned to bring this forward. I saw Dr Charles Millson who diagnosed ascites, this is a build-up of fluid in the abdomen caused by the liver not functioning efficiently.

28. He wanted to admit me to the hospital straight away but there were no beds available so I went in the next day. I stayed in for 6 days while the fluid was drained and had further biopsies and scans. In order to drain the fluid they had to make incisions in my abdomen and fit tubes that drained the liquid directly from my abdomen into an external bag. I had to walk around the ward with a bag full of this fluid, which was not very pleasant.

29. It was at this point that I was put on the transplant register but I was advised that it could take up to a year for a liver to become available.

30. During this stay in the hospital, the consultant advised me to sue. I said that I had given it some thought but would have no idea where to start, botched D &C, transfusion?? and until there was a class action I would not be able to afford the costs. The consultant thought that there would be many cases like mine as he said blood was not screened until 1981.

31. Throughout the time that I was waiting for a transplant I could not go on holiday as I had to be ready in case a donor was found. This was hard for my husband and myself as both of our children lived abroad. I think it was at this stage we asked what would happen if I didn't have a transplant. The answer was that I would die of liver failure.

32. I went through many more clinic visits and blood tests. Until, on the 17th November 2006 I received a telephone call very early in the morning (5am ish) to say that they had a donor liver and I was to make my way to Leeds hospital as soon as possible.

33. The operation for my liver transplant took place from about 3pm and took approximately 8 hours. I was transferred to ICU after the operation and then transferred to a normal ward.

34. After a further 2 to 3 days on the ward, two consultants came to my bedside and told me that the multi organ donor had a renal cell carcinoma on one of her kidneys and that I would therefore have to be monitored.

35. I said to the consultant that this was a "double whammy" for me, (meaning I was here because of the infection and now being told this news) They were not sure what I meant. However, he came back later after looking at my medical notes and he agreed. In total, I spent 12 days in the hospital.

36. Prior to finding out about the infection I had noticed that if I had a drink I did not seem to be able to process it, I got headaches easily and my eyes looked glazed even with just a small amount of alcohol. My husband always commented that even with one or two drinks he could smell the alcohol on my breath the next day even though he had the same amount.

37. It was St. James's Hospital that confirmed that I had been infected with HBV. I was advised to cut out alcohol altogether, which I did and that eventually I would need a liver transplant but they could not say when this would be. Other information was given about precautions to take

which I followed. I do not think that information could have been provided earlier.

38. The information that was provided to me about the Hepatitis was of course a shock but I knew this was something that I was going to have to live with. The doctors talked about it all very matter-of-fact which they are used to doing as they come across lots of cases like mine but this was a very hard time for me and my family.

39. From our initial consultation at St James' hospital my husband and I were advised to practice safe sex. I had to be careful around my daughters and always had to be careful and hygienic when preparing food in case I cut myself as this could affect the food.

Section 3. Other Infections

40. In 2012 from both conversations and letters I received from Leeds hospital it appears that I have also been infected with Hepatitis D. You cannot get HDV without HBV. I cannot remember when I was first made aware of this.

41. I know that special blood tests are carried to find Hep D and they had to be sent off to a separate lab. I had to go through to Leeds Hospital for this in the early stages as my GP could not do it. Most of the tests were done on my routine visits to the Liver Clinic but sometimes I had to make a separate trip which was about 60 miles round trip. I was told that the prognosis of having Hep D was no worse and in fact could be a little better than Hep B alone.

Section 4. Consent

42. I do not believe that I have been treated or tested without my knowledge, consent or without being given adequate or full information. At the time of admission for the second D&C I do not think I was in a fit state to comprehend what was going on around me. I probably did need the transfusion and probably would have signed a consent form

but I cannot remember whether I was given the option, which I may have taken. I do realise that they were acting in my best interest.

Section 5. Impact

43. My HBV infection is always on my mind and is brought up whenever I meet people asking how I am. Towards the end of my wait for a donor I was getting increasingly more tired, listless and fatigued. We were managing to still do our hobby of walking but the distance covered was decreasing as the months went by.

44. I also had to stop playing badminton and swimming as I no longer had the energy. I kept working but as I was working from home and only part-time this was not as much of a problem, my boss was also very understanding which helped.

45. With all the medication that I am on, it has impaired my kidney function and now I have been diagnosed with chronic kidney disease. I was under the care of Doctor Border at Harrogate hospital but now my kidney function is monitored by blood tests at my GP.

46. I have also had a diagnosis of osteopenia and I'm taking Alendronic Acid tablets. I was on these for 2 years, up to November 2019 but then I was advised to stop taking them as they had had the desired effect but to have a further bone density scan in 2 years. Further bone density scans in April 2022 indicated that I would benefit from taking this medication for another 3 years and then after that I would need a further scan. This is all as a result of the medication.

47. Further to this, I have received a total of 6 covid jabs. I had two AstraZeneca jabs and 4 Pfizer. After my first Pfizer jab I had very bad side effects. I had all the symptoms of pericarditis (inflammation of the lining outside the heart) and spent a full day in bed. After the second jab I had a day in bed with flu-like symptoms. After my third and fourth vaccinations I had a bad night and the next day I fainted and had to stay in bed for the rest of the day. Whether these side effects are due

to the immunosuppressant drugs we will never know. I have made a full recovery from these side effects.

48. The main source of treatment that I have had for my HBV was my liver transplant in November 2006. Due to the damage on my liver caused by the undiagnosed Hepatitis, I could not have the interferon treatment. I do not know whether there were alternative treatments which I could have had.

49. After a few years of getting repeat prescriptions from my local GP surgery refused to supply some of the medication from the surgery itself. I think this was due to the cost and so I had to go to the local chemist. We live more than 2 miles from the surgery, so they should have supplied it.

50. We only found out about this in May 2013 when we called to collect the medication, this was a bank holiday Friday. The receptionist said that they had had a change of policy and would not be supplying Advagraf, my then anti- rejection medication. She said they had tried to phone me but didn't leave a message. I always request my repeat prescriptions about 2 weeks prior to needing them.

51. This was incredibly stressful for me as I need to take this medication twice a day, every day to prevent liver rejection. The doctors should have known this.

52. The receptionist at the surgery was very helpful, I am grateful for her for her help. She phoned a local chemist who was able to obtain these and I was able to pick them up on bank holiday Saturday. I was worried I would need to make the 60-mile trip to Leeds hospital. I moved all my medications over to that chemist so I didn't have to collect from two separate places or risk the medication not being in stocked at the GPs medical centre.

53. I received a compliment slip from the Doctor GRO-B dated 15/5/13 at the surgery apologising for 'trouble' about my medication and transferring me over to the local chemist for future prescriptions.

54. The impact of my Hepatitis has curtailed a lot of things that I had planned. I cannot go on all the holidays I wanted to and planning to go and visit family is becoming increasingly difficult. I find telling new people that I meet that I am infected embarrassing, I don't like having to revisit the subject.

55. I found it difficult that in all my appointments my medical notes were always covered in big yellow 'hazardous' stickers. It just seemed to highlight that I was subject to infected blood. I had to walk around to get blood tests with the stickers all over my notes, I found this humiliating.

56. Our daughters have taken it in their stride but when it comes to visiting them in their country, it is touch and go if we can make the journey because of the rising cost of insurance.

57. Socially, I had to stop playing my weekly badminton and swimming and therefore lost touch with some people. I am now back at badminton which is good.

58. I was not allowed to travel until a year after the transplant. Since 2007 we have tried to visit the family annually but had to pay a supplement on the travel insurance to cover me in case I got sick abroad. Our last visit was to New Zealand and then Australia to visit family. We got back just 10 days before the COVID lockdown on the 23 March 2020.

59. We have planned a return trip to NZ and Australia for February 2023. However, trying to get travel insurance is a total nightmare, some declined to cover me at all, and the prices are ridiculous. Over £2,700 for a single trip. We used to have travel insurance through a package bank account but they have declined to cover my conditions - liver transplant, osteopenia and chronic kidney disease.

60. Because of this we may not be able to visit our daughters, especially our eldest in the USA as most companies won't even quote for us to go there, as the cost of medical care in USA is so high. The thought of not

being able to travel to see my daughters is completely devastating. I have found this to be one of the hardest impacts to deal with.

61. During the COVID lockdown from 23 March 2020 I was advised by the government that I should stay at home, which during the first lockdown period I did. Never leaving the house and garden for 115 days and not seeing anybody face to face.

62. After that when we were out walking we gave everyone a wide berth and went on walks where we would not see anybody. I found this very isolating.

63. I do feel that I was kept informed by the Government during the lockdown of ways to stay safe. I was offered advice on where to get help, I had numerous telephone calls checking in that my husband and I were okay. I felt like the government looked after at risk people like me.

64. We did not tell anybody, apart from our daughters about the Hepatitis infection until January 2006 when I was admitted to the hospital. I felt it was too embarrassing and my daughters felt the same and kept the infection a secret.

65. The infection did not impact my education as it wasn't until later in life that I was infected. My employer has always been very understanding. I had to take a period of time off work from the date of the transplant for approximately 4 weeks. But as I worked from home I did the work when I felt fit enough.

66. From July 1999 until I reached that age of 60 on GRO-B 2007 I had to pay prescription charges for all the medication I was prescribed. We also had to make our own way to all the hospital appointments, lots of which were over 30 miles away in Leeds.

67. My travel insurance costs have been the most frustrating of the financial burdens as a result of my infection with Hepatitis. This

prevents me from seeing my family which has been very difficult for me.

68. The entire situation has been very difficult for us all, as a family. They are grateful that I received a donor liver and have had no problems since the operation 16 years ago.

69. Without the operation I would have died, it is hard to think that someone had to die so that I may live.

70. From August 2022 I am now monitored annually via phone calls with my consultant. The doctors seem happy with how my body is coping with the transplant so my check-ups have been reduced from in person to over the phone.

71. My current prescription of medication is exhibited as **WITN7324003.**

Section 6: Treatment/ Care and Support

72. I do not think that I have faced obstacles in obtaining treatment. Once I was diagnosed, the medical intervention seemed to happen as quickly as it could.

73. I was not offered psychological support, I do not think that I would have taken it if it was. I speak to my husband and I deal with it in the best way that I can.

Section 7. Financial Assistance

74. I have not received any form of Financial Assistance.

Section 8: Other Issues

75. Some of my family and friends who know my medical history are under the impression that I am in for a large payout of £100,000, having seen and heard the news bulletins from the Inquiry. It should be made clear by the Inquiry team that not "all" infected people come under the terms of the Inquiry at all.

76. I understand why the Inquiry was set up, as young children with haemophilia were given infected blood products and group action was demanded by parents. If compensation is issued to these patients only, it should be made clear in the news bulletins that not all people who have been infected with contaminated blood will be dealt with under the Inquiry remit or receive any money for expenses we have incurred as a result of receiving the infected blood.

77. I would like to understand the reason Hepatitis B is not covered in the same way as Hepatitis C as the outcome for the patients is likely to be just the same.

78. I would also like to note that I requested a copy of my medical records from St James' Hospital on 25 July 2022 but as of yet these have not arrived.

Statement of Truth

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

Signed GRO-B

Dated 21/11/22