Witness Name: GRO-B
Statement No.: WITN0139001
Exhibits: None
Dated: 17 April 2019

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 February 2019.

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 known to the Inquiry. I am a retired nurse, married with one son (born 1971, now sadly deceased) and two daughters (born 1973 and 1978).

2. I intend to speak about my infection and touch upon my younger daughter, GRO-B: D infection with Hepatitis C. I will not go into detail about my daughter's illness, as she intends to provide her own statement to the Inquiry. In particular, I will speak about the nature of the illness, how the illness affected me, the treatment that I received, and the impact it had on my family and myself.

3. I have been asked if I am legally represented; I have had contact with Leigh Day Solicitors but I have not consented for them to represent me. I am happy for the Inquiry to take my statement.

Section 2. How Infected

1. I was infected with Hepatitis C in September 1974 at what used to be St James's Hospital in King's Lynn (now replaced by the Queen Elizabeth Hospital, King's Lynn). I was in hospital and required a blood transfusion on that occasion because I had septicaemia due to another medical blunder.

2. At the time, I was married with two children. My son was born in 1971 and my daughter was born in 1973. After my daughter's birth, I did not want any more children for a while so I had a contraceptive coil fitted. It worked well for a few months, but then I started to realise that I was pregnant again. I decided to keep the baby, even though the pregnancy was unintended.

3. In the 70s, it was apparently medical practice to keep the contraceptive coil in place, even after a woman became pregnant, so my coil was left in. However, I gradually started to become ill as my pregnancy progressed. My doctors thought that I had a urinary tract infection (UTI) and kept treating me for UTI. But then, at 20 weeks pregnant, I was rushed into hospital with septicaemia.

4. When I arrived at St James's Hospital, I was almost at death's door. I had lost about a stone in weight already, due to the septicaemia. I went into septic shock and sadly suffered a miscarriage. If the miscarriage had happened today, I would have been able to see the baby and deal with the remains in an appropriate manner. However, in those days, the medical staff put the baby straight into the incinerator. I did not get to see my baby, or find out whether it was a boy or a girl. Even now, 45 years later, I would still like to have known if my baby was a boy or girl.

5. After the miscarriage, I was in hospital for about a week during which time I was attached to drips and had blood transfused into me. I recall hearing that I was anaemic, which was why I was given a blood transfusion. I believe that I would have recovered, albeit more slowly, without the blood transfusion, but I think that the hospital wanted to discharge me from the ward as soon as possible.

6. I continued my recovery at home, though it took a while for me to get back to normal. I became tired quite easily during this time, but I put it down to the fact that I had two young children and had been very ill with septicaemia.

7. A few years later, I became pregnant again. My second daughter D was born in 1978. If I had known that I was infected and infectious at that time, I may probably have thought twice about having another child. However, of course, I did not know that I had Hepatitis C then or until some years later. I had D and then for about 13 years my family and I lived in blissful ignorance. I still got tired very easily, but I thought it was due to my history with septicaemia. There was nothing to indicate that I was ill due to problems with my liver.

8. I did not find out that I had Hepatitis C until 1991. Even then, I was only informed that I had Hepatitis C because I had been donating blood, and 1991 was the year in which screening for Hepatitis C was introduced. I had already been donating blood for around ten years by that time, and the blood had always been accepted.

9. However, in 1991 I remember that I had been shopping, and came home to find that there was a letter from the NHS blood transfusion service saying that they no longer required my blood because I had Hepatitis C. The letter stated that they would be in further contact with me, and that they would not accept any blood donations from my husband as a matter of policy.

10. I was shocked and upset, firstly to find out this news and secondly to be informed of it in this manner. The letter did not explain what Hepatitis C

was. I think the term "non A non B hepatitis" was still used in those days. I do not recall being given any other information about Hepatitis C.

11. I then had an appointment arranged to go to Addenbrooke's Hospital in Cambridge, where they had a blood transfusion centre. My doctor was a lady called Dr Cafrey. She informed me that I did not need to worry about Hepatitis C, because she thought that I had contracted it but had already cleared it by myself. At that stage, I do not know whether the tests had detected HCV antibodies or the virus itself.

12. After the initial appointment at Addenbrooke's blood transfusion centre, I was transferred to the hepatology department. They started seeing me quite regularly. I believe that they were also seeing many other donors who had been identified as HCV-positive by the new blood screening procedures. I still did not have any symptoms of Hepatitis C that I was aware of, and my liver function test results came back as relatively normal, although there was one particular enzyme level that was detected as normal for Hepatitis C.

13. At the time when I was diagnosed in 1991, I did not think to have the rest of my family tested. None of the medical staff ever suggested anything of the sort, so it just did not occur to me that they might be infected. I did not see how that could be a possibility. However, a couple of years later my daughter was researching more about Hepatitis C and read that it could be passed on from mother to unborn baby 'in utero', so I thought it would be best to have D tested.

14. I believe it was around 1993 when we went to the GP surgery to have D blood tested for Hepatitis C. D was only fifteen years old at the time.

15. I was told of D test results when I went to enquire at the receptionist's desk: "She's positive". That was all that the receptionist said to me and in an open area. She did not even say the words "Hepatitis C". It was as if the receptionist had no care or understanding of the devastating implications

of what she was saying to me. The GP should have looked at the blood test results and called me into a private room to discuss the results with me, instead of me being told the results in public by the receptionist.

16. None of my other family members have ever been tested for Hepatitis C. My other daughter has thought about having the test done, but she has never exhibited any symptoms for the disease so nobody has ever suggested that she be tested. I think that GRO-D only got the infection from me because I was probably quite infectious when I was pregnant with her. I assume that I had quite a high viral load at the time because I had only received the blood transfusion a few years before that, and I had been quite ill at the time.

17. With regards to information concerning the risk of infection to my husband, I recall that my GP was going to give me a free supply of condoms. However, when I asked the medical staff at Addenbrooke's about it, they told me that there was no need for such precautions. I do not recall being given any other information about the risks of infection to others.

Section 3. Other Infections

18. I have cirrhosis as a direct result of having HCV. I do not believe that I have received any other infection as a result of being given infected blood.

Section 4. Consent

19. I do not believe that I have ever been treated or tested without my knowledge or for the purposes of research.

20. I do not recall consenting to the blood transfusion in 1974, but then I was not in a position to give consent as I was very ill at the time. I would not have refused the transfusion if the doctors had advised I have it. I was not informed about the risks of HCV transmission associated with blood transfusions, and I would not have consented to receiving contaminated

blood. However, given my condition at the time, I was not in the position to make a decision.

Section 5. Impact

Mental and physical impact of infection

21. With regards to the physical impact of being infected with Hepatitis C, I did not have any symptoms that made the doctor suspicious. There was nothing that obviously indicated that I had Hepatitis C.

22. I had post-natal depression after I had septicaemia, but I believe that was more due to everything to do with losing my baby at 20 weeks than something HCV-related. I had no reason to believe otherwise, at the time. I was also easily tired, but I thought that was a consequence of having young children. Any mood swings that I had, I attributed to hormones. My digestion was fine; I was not feeling sick or vomiting.

23. I did develop dreadful insomnia, but I had always believed that was related to my anxiety. However, I have more recently learned that liver disturbances can result in insomnia. I was diagnosed with cirrhosis of the liver in December 2015, but again I did not have any symptoms that alerted the doctors to significant liver damage until my first fibroscan detected it. I asked the doctors why I did not feel more ill, and they told me that it was one of the problems with Hepatitis C – you can feel fine for a long time until your liver suddenly fails.

24. The infection has had a much bigger impact on me psychologically. I had been donating blood for around ten years by the time I was diagnosed, so the thought that I was unknowingly infecting other people haunts me. However, the main thing that I could not get over was the fact that D contracted the infection from me. I knew that it was not my fault, nevertheless I still felt so guilty. This has been the worst aspect of having

Hepatitis C – knowing that I had unwittingly infected my daughter when I was carrying her and seeing the infection have an impact on her life. D is always reassuring me that it was not my fault that I passed the infection to her, but if she had died as a result of it, I would never have forgiven myself.

25. D now has two children, but initially she was not sure whether to have children because she did not want to pass the infection to them. Her children were tested at birth for Hepatitis C, but I do not believe the tests were especially stringent or accurate, so the fear is always in the back of her mind.

26. Once I knew that I was infected, I stopped drinking alcohol completely. I did not drink a lot before but I did not want to risk any further damage to my liver. I know that not drinking alcohol should not be a big issue, but in the past, people would sometimes look at me and wonder what was wrong with me if I was not drinking. They would think that I was being a "party pooper" or else at the other end of the scale, that I was recovering alcoholic.

27. I would have liked to have the occasional drink as I tend to enjoy parties more that way, but I do not drink at all now. I fear that the scarring on my liver will turn to cancer, and the damage is irreversible as far as I am aware.

Impact of treatment

28. After my diagnosis in 1991, I was monitored at Addenbrooke's and attended regular check-ups, either every six months or every year. However, I was not offered any treatment until December 2015 because I was considered not ill enough to warrant a course of treatment. Maybe if I had been treated earlier I would not now have cirrhosis.

29. D condition was similar; she was monitored by Addenbrooke's following her diagnosis in 1993, but was not treated until quite recently.

30. My check-ups usually consisted of numerous blood tests and ultrasound scans. I did have one liver biopsy quite a long time ago – I cannot remember when. They stuck a needle through my ribs when I was only under local anaesthetic, so it was quite a traumatic experience. My biopsy revealed that I had mild scarring on my liver, so the doctors wanted me to undergo another liver biopsy. However, I refused because I did not see the point of repeating the trauma when they could not treat my hepatitis anyway.

31. D also had liver biopsies. The doctors had to conduct two biopsies on her.

32. D and I then had fibroscans a few years ago. It was not invasive like the biopsy procedure. D had her fibroscan first, and her result was not too bad. She had quite a low score. However, the result of my fibroscan then came back in December 2015. I was informed by a letter through the post that I had significant liver damage with cirrhosis, rather than just mild scarring as initially thought. Because of this, they immediately started me on a course of Harvoni and Ribavirin. I also had a gastroscopy (camera down the throat) as liver disease can cause a type varicose vein called a oesophageal varices that can cause bleeds. Thankfully none were found but the procedure was traumatic, even though I had a mild sedation. I had never realised that this was another aspect to having the infection and it was yet another ongoing concern for me.

33. I was on the treatment of Harvoni and Ribavirin for three months, from December 2015 until February 2016. This was administered through tablets, which I had to take daily. The treatment made me feel quite ill. I suffered nausea, and terrible mood swings known as "Ribavirin rage". It was like pre-menstrual tension but far worse: I would get upset very easily about things and have extreme emotional reactions. My husband took the brunt. I also had flu-like symptoms, such as tiredness and constant headaches.

34. After a fortnight of being on this treatment, I was tested at the hospital to see if I was responding. For some people, a fortnight on this treatment is

enough to clear the virus. I had not yet cleared it as I had had a very high viral load before I started on the treatment, but fortunately the test showed that my viral load had fallen, so I continued with the treatment.

35. I finished the treatment around February or March 2016. Three months later, the doctors confirmed that I had cleared Hepatitis C to a stage where it is now undetectable. Therefore, I am now clear. However, I still cannot give blood, and the hospital are still monitoring me in case the virus comes back. So 'clear' does not appear to be definitive, because I think they just do not know for sure yet, if the HCV can re appear.

36. This is my main worry now; my last test was in November and the next one is due in a couple of months. In between tests, I tend to forget about Hepatitis C, though it is always somewhere in the back of my mind. However, as the tests draw nearer, I become increasingly nervous. I am especially worried for my upcoming test, as I will have a fibroscan and I do not know what the results will show; I know that cirrhosis can lead to cancer. Even though I have cleared Hepatitis C, I cannot say that it no longer affects me because it is always a worry that it could come back.

37. D is fortunately now also clear of Hepatitis C. She only cleared it 3 – 4 months ago, as she was only allowed to start on the course of Harvoni and Ribavirin sometime after I was given it. She had to fight to get access to the treatment, because initially she was not considered to be ill enough for it. She was not happy about this, because she had already sustained damage to her liver. D did not want her condition to deteriorate knowing that there was a treatment available, which she had seen work for me.

38. Fortunately, the hepatology nurse at Addenbrooke's was very lovely and supportive; she fought D s corner and got her accepted onto the Harvoni treatment. The hospital do not make the treatment widely available to everyone because it is expensive, and they prioritise the most ill people, which I can understand to a degree. Therefore, even when D was granted access to it, the hospital only put her on the treatment for two months (instead of three like me).

39. D cleared the virus after this two-month course, but then three months later after a check-up, the doctors found that the virus had come back. The doctors called D a "non-responder", and said that it was a very unusual case. My daughter then asked to be given Harvoni again, since her course of treatment was one month shorter than mine, but she was refused as the hospital said they could not treat non-responders.

40. After that, a new drug came out which was to be administered with Harvoni. Fortunately, D was given that treatment. She has finally cleared HCV as a result.

41. I have constantly to be monitored due to my fluctuating platelets. At one point prior to my treatment, I was shown to have a very low platelet count, which was a cause for concern. It was fortunately never low enough to necessitate another transfusion but like other things it is just another worry. I am still tested for this.

42. Overall, I may not have succumbed to the disease as seriously as others. However, all of these things are a constant concern in my mind, worrying that something may develop.

Impact of infection on access to other medical/dental treatments

43. I have not experienced any significant obstacles to treatment as a result of being infected with Hepatitis C. However, there have been instances when I was treated differently due to my infected status.

44. For example, I was always given the last appointment of the day when I had gynaecological treatments at the Queen Elizabeth Hospital in King's Lynn. I could see how that was a sensible precaution to take, nevertheless it made me feel awful. I noticed that my medical notes were also marked out with a yellow sticker, to signify my infected status.

45. My previous dentist was somewhat unpleasant when I told him I had Hepatitis C – I recall that his actual words were "bloody hell, that's a killer".

It was not a nice thing for me to hear. He said that he would have a look at my teeth, but if there was any blood involved he would have to send me to the hospital. I did not know what to say to his response, so I did not say anything.

46. I have never experienced any other obstacles to treatment, but there have been occasions where I felt guilty for not mentioning the fact that I had Hepatitis C. I was bitten by a dog once when I was working as a district nurse, and I was stitched up by a doctor. He wore gloves whilst attending to me, but I felt like telling him to be more cautious anyway. However, I could not tell him that I had Hepatitis C because I did not want other people at work to know. I felt guilty afterwards, like a secret pariah.

Financial and work-related effects

47. I qualified as a nurse in 1988. Prior to that, I had been a PE (physical education) teacher for three years. When I received my Hepatitis C positive diagnosis, I was told by occupational health therapists that I was allowed to carry on nursing. This was because I was only a general nurse and did not perform any invasive procedures. Therefore, I carried on working, but the infection affected me mentally. I was always very conscious that I had Hepatitis C when I was around patients. I was also anxious that someone would find out about my infection, and that there would be repercussions.

48. However, I was physically able to continue working as I did not experience many symptoms of Hepatitis C. I believe that this was partly to do with the fact that I was always quite health conscious; I was careful to look after myself by eating healthily, doing exercise and refraining from drinking alcohol. Consequently, the main financial impact of having Hepatitis C has been the fact that I had to repeatedly travel down to Addenbrooke's on the train.

49. I have never had problems with obtaining travel insurance, although this could be because all of my travelling has been within this country.

Impact of stigma

50. The stigma attached to Hepatitis C has stopped me from sharing my experiences with many people. Apart from close family members, I have only told three close friends whom I trust not to tell anyone else. It is the same with D She has not told any of her colleagues, because she is scared of how she would be treated otherwise. It might be that people would think that they cannot share mugs with her in the kitchen, or something similar. I have not had many problems with stigma, but that is because I have not told many people.

Impact on family

51. My husband is a very taciturn person, but I know that my infection worries him. I can see that he is concerned about me, and he is always there to support me when I become anxious about going to Addenbrooke's for tests.

Section 6. Treatment/Care/Support

52. I have never been offered any psychological support or counselling in relation to Hepatitis C.

Section 7. Financial Assistance

53. I have received financial assistance from the Skipton Fund. I believe that I found out about Skipton through Addenbrooke's. From what I recall, the application was fairly straightforward because Addenbrooke's handled it for me.

54. The Stage 1 payment of £20,000 came quite quickly after I submitted my application. I was quite surprised by the promptness of the payment. It quite a lot of money for us to receive at once. I then received the Stage 2 payment of £50,000 since I had cirrhosis, and I got monthly payments of £1500 per month which has recently increased to £1800 per month. I also receive a £500 winter fuel allowance in addition to this.

55. I feel slightly guilty about receiving this money, because it is more than I have ever earned in my life. Perhaps it shows that the NHS or the government are trying to compensate for their wrongdoing in giving me Hepatitis C in the first place.

Section 8. Other Issues

56. Although I have been relatively fortunate with the fact that I have not suffered many noticeable physical symptoms of Hepatitis C, it still makes me angry that I was infected when the risks of transmission through blood transfusions was known. I now have to worry about the fact that I may have infected others when I was trying to do some good in donating blood, and I still feel guilt that I infected my own daughter.

57. I am further angered by the manner in which I was told of mine and then D infections. Although I am now clear of Hepatitis C, it is still very much present for me because I fear that it will return, as it did for D Hepatitis C has unfortunately become so much a part of my life that living with it has become the norm.

Statement of Truth

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

Signed GRO-B

Dated 17.4.2019