Witness Name: GRO-B
Statement No.: WITN0837001
Exhibits: None
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 21 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 1963 and my address is known to the Inquiry. I am married to GRO-B: W and we have four children and six grandchildren. I intend to speak about W infection with Hepatitis C. In particular, I will speak about the nature of her illness, how the illness affected her, the treatment she received and the impact it had on her and our lives together.

Section 2. How Affected

2. I have been married to my wife, W, for GRO-B years. I have known her since I was 19 years old, when we were both working in the GRO-B

GRO-B together. We have four children, namely GRO-B (born in 1987), GRO-B (born in 1989), GRO-B (twins, born in 1991).

3. W was infected with Hepatitis C after giving birth to our children. I cannot be sure of the date that she became infected, as she received transfusions following GRO-B birth in 1987 and the twins' births in 1991. I have always personally believed that she was infected after the birth of GRO-B our first child, in 1987. She received a blood antibody card (exhibited in W statement as GRO-B following that transfusion. However, it is possible that she was infected after the birth of the twins in 1991.

4. On both occasions, W required blood transfusions because she had lost a lot of blood when giving birth. I was present for all of our children's births as I found them fascinating, so I witnessed W receiving the blood transfusions.

5. When W received the blood transfusions, we were not given any advice or information about the risks associated with blood transfusions. We were not told about the risk of infection on any occasion. We just assumed that the doctors knew best and that they had W best interests at heart, so we went along with their advice without asking any questions.

6. I did not realise that there might be something seriously wrong with W until she started working for GRO-B from July 2014. She experienced mood swings before that, but it was the weight loss whilst she was working at GRO-B that I really noticed. Her weight loss was drastic. Our friends and family started to comment on it before I did; I was a bit slower to notice as I was with her all the time. However, once it was pointed out to me, I saw that W had lost quite a lot of weight quite quickly.

7. After that, I noticed that W really started to experience fatigue. She began losing her hair and her hair colour started to change. I attributed these symptoms to her diabetes, which was only diagnosed in 2004. I also

assumed that she was fatigued and generally run down due to working at GRO-B I did not know or suspect anything about Hepatitis C at this time.

8. Indeed, W and I did not find out about Hepatitis C until November 2015. My memory of this time is vague, as I was shocked and numbed by her subsequent diagnosis. All I can recall is that she had been to see the doctor and he had conducted various tests on her. He then called her, and informed her over the telephone that she had Hepatitis C. I did not hear the conversation on the phone myself, but I have been told about it by W She informed me that all the doctor said was that he was sorry, but she had Hepatitis C.

9. We were both completely shocked by this news. I cannot remember that day very well, because we were just walking around feeling numb. I did not know what Hepatitis C was at the time, and we were not given any other information so I was left with the task of finding out about the disease we were facing whilst I was in a state of shock.

10. I believe that W and I should definitely have been given more information about Hepatitis C when she was first diagnosed. Any information that we did gather, we gathered ourselves. As far as I recall, the doctors only gave us a very quick, rudimentary explanation as to what Hepatitis C was and what it entailed. I cannot remember being given any detailed information. We did not have anyone to sit down with us and explain everything.

11. I was in fact tested for Hepatitis C by my own doctor, at my instigation, on two separate occasions. Fortunately the results came back as negative on each test.

Section 3. Other Infections

12. I do not believe that W received any infection or infections other than HCV.

13. However, I was concerned for a while that she might have been infected with HIV. This was because I saw that "HIV" was typed on one of her medical notes. There was no explanation why "HIV" was typed on her notes. Fortunately, W does not have HIV, but I am at a loss as to why it was typed on her notes in the first place. It caused us a lot of concern, because of course it was the last thing that we wanted to see.

Section 4. Consent

14. W underwent various test with her consent and knowledge. However she was at one point advised she had tested negative for the Hepatitus B virus, a test, she was unaware she had been subjected to.

15. I don't think W was treated for the purpose of research at any stage but it would be fair to say that she was given little or no information prior to receiving treatment.

Section 5. Impact

Impact on W

16. The impact of infection with Hepatitis C on W has been enormous. It has completely changed who she is, such that she is a totally different person now from the woman I married 34 years ago.

17. As stated above, the physical effects of infection that W experienced included dramatic weight loss, fatigue and hair loss. More significantly, the virus has caused her to develop cirrhosis of the liver. The treatment W has had to receive to combat the infection and cirrhosis has made her fatigue worse; she can now sleep for up to 18 hours per day.

18. Since being infected with Hepatitis C, W has also experienced astronomical mood swings. She goes from being "on a high" – happy, bubbly and bright – to being very low in mood. I only wish that the highs

would last as long as the lows. Her low moods last 2-3 days on average, but can last for up to a week although the severity will vary throughout.

19. When W is feeling low, it exacerbates her fatigue and she will just want to sleep all of the time, because that way she does not have to think about anything. The fatigue has taken a lot of joy out of life for her, because she is not able to do the things that she used to love. For example, she used to love gardening, but now it is often not worth the effort for her anymore. She did not used to be like that.

20. W can also become tearful from the slightest thing now. For example, she might become very upset at something I have said that is not meant in the way it is received, or she might get upset at household items being put in the wrong place. The smallest thing can trigger floods of tears when W is already feeling down.

21. Naturally, this has hugely changed the dynamics of our marriage. I sometimes feel like I am treading on eggshells around her.

22. I try to take her mind off things by suggesting things like going on holiday in our caravan, but when we did that recently, W would get so tired that I would just end up doing things by myself. I do my best to support her, but I know that the inability to do all of the activities she is used to doing has been very difficult for her to deal with. She wants to carry on as before, but she is just not mentally or physically able to.

23. Being ill with Hepatitis C has taken away many opportunities from W We would both still have been working today if was not for this illness. She was doing so well in her last job working for GRO-B and I could see that being reflected in her overall confidence levels. But now, with her ongoing health problems relating to HCV, I cannot see her ever getting back to a point where she is confident and energetic enough to be doing things like making promotional films at GRO-B

24. However, I do believe that she has benefitted a lot from running her support group, GRO-B It has been a tremendous help to

her, because she is able to meet people through the group who have the same condition, and they can share their experiences with each other. As much as I try to read all that I can about Hepatitis C to understand better what she is going through, it will never be the same as talking to another infected person because I have not experienced it personally.

25. With regards to accessing treatment, W had some difficulty because the Norwich and Norfolk Hospital offered treatment, then took it away before agreeing to offer it again. Initially, they informed us by post that W was eligible to receive a new treatment for Hepatitis C. However, they later withdrew the treatment for W, saying there was a lack of funding for it. The hospital said that they could only treat two people per month instead of eight and that as a result, W was no longer eligible. Then, after W contacted the hospital to challenge their decision, they agreed to offer her the treatment again.

26. I believe it was around September 2016 when W was eventually allowed to start the treatment, several months after she had been diagnosed in November 2015. The waiting and the constant changing of responses from the hospital made this period more unsettling for us because we did not know what we could expect.

27. Thankfully, the treatment was successful and W cleared the virus so that it is now undetectable. Nevertheless, it has had a long-lasting impact on us and I do not believe that the treatment has improved W physical condition overall. W still suffers the side effects of the treatments today, as I have described above.

28. I have been asked how W infection with Hepatitis C affected our private, family and social life. It has stopped us going out, as W would usually be too tired. She is now much more reclusive and just wants to stay at home all the time. I try to encourage her to go out, but W feels safe in her home environment, whereas she gets anxious when she is outside.

29. Even most of our shopping has to be done online now, because I know that W will only last about 15 minutes in the shop before she will have to rest. When we used to go out, I would have to finish the shopping by myself. Then when we got home, W would go straight to bed or fall asleep on the settee, and I would put all the shopping away. It is no longer worth the effort for us to go out, so we just get everything delivered now. Without a doubt, this illness has turned our lives upside down.

30. Although I was not personally infected with Hepatitis C, it has still had a huge impact on my life. It has completely changed our marriage, as W became increasingly less able to do the things she used to do. Our roles were set for years before things totally changed.

31. Before she became ill, W did everything pertaining to the running of the family home. She always managed everything and paid all the bills, so it came as a shock when I had to take over the running of the house and manage everything alone. Now, I do all of the housework, I make sure that W has taken her tablets on time and I even help her shower as she is unable to get in and out of the bathtub independently. I am her full-time carer, as well as manager of the house.

32. I have had to give up work in order to become W full-time carer. This has impacted our finances, and it has also caused me to gain weight because I am less active now than when I was working.

33. Watching someone I love get worse with illness and become lower in mood has completely drained me mentally. It has been such a stressful experience that I still have trouble sleeping, even now. I find myself sitting awake on the settee most nights. W infection has left me with mild insomnia, because there are so many things on my mind that I can never fully settle down and relax.

34. It hurts me to see that the person I knew and married is not there anymore. I see flashes of the person W was before the virus took over our lives,

but I cannot go even two or three days without seeing W become fatigued and go to bed all the time.

35. It is very difficult to stay positive and provide encouragement for someone 24 hours a day, seven days a week. It is difficult to try to be jolly all of the time. But at the same time, it is no good for us both to just be sitting here, wallowing in sadness. So, I try to pick myself up, push myself along and encourage W as well.

36. I was initially so unprepared for dealing with the infection with W. I had no idea how it would affect her, so it actually surprised me when the virus changed our lives as much as it did. At the beginning, I was just trying to get my head around coping with Hepatitis C and understanding how it was affecting W.

37. Now, I have learned to wait and see how W is feeling on any given day to gage how the rest of the day may unfold, because her condition can change a lot from day to day. I do not know whether W will be bright and bubbly, or sad and downcast until she has been up for about 5-10 minutes in the morning. Sometimes we are both in this house, but it is totally silent. We co-exist without saying anything to each other. At some points, we have gone a couple of days without really speaking.

38. The mental stress of dealing with W infection is reflected in my body physically: I now have constant flare-ups of psoriasis. I have had mild psoriasis since I was young, and I notice that my flare-ups are usually stress-related. It always gets worse during stressful periods of my life. Previously, I would only have flare-up once a year, but now my psoriasis is constantly bad and irritated. It started getting worse after W diagnosis of Hepatitis C.

39. I have never had anyone to talk to about my side of the struggle with W infection. I have never met any other affected partners, but I am sure that my struggles are not unique to me. I would like to be able to speak to someone who is in the same position as I am, so that I do not have to

feel so isolated. I do not talk to my daughters much about it because they live further away and have very busy lives of their own. I know that they also do not like talking about W illness much. I do not really want to talk to W about it as she has her own struggle to deal with, so I just keep my feelings to myself.

40. Because I cannot talk to anyone, I just sit in the living room with the TV on and just reflect about things. I keep it in because I do not have an alternative, but sometimes it does get on top of me a lot. It has been quite overwhelming and isolating. I strongly feel that affected people should be given much more support, because we currently receive none.

41. It would have helped me a lot if someone had only explained properly, at the beginning, what fighting this disease would entail. I should have been told more about the tablets W had to take, such as what they were, what they were supposed to do, and the kind of side effects to expect.

42. Another example of when I was not given enough information was when W went for a fibroscan. I had no idea what a fibroscan was, and no one explained it to me. I remember W getting 39.1 on her fibroscan result, but I had no idea what that meant, and again no one explained it. The hospital only told us not to look up the result on the internet, but of course that was the first thing I did in the absence of any other information.

43. Even though the Hepatitis C is classed as undetectable now, there is not a day that goes by where the long-lasting effects of the virus are not in our lives. We do not get a weekend off. Every time W goes for a scan, I worry in the back of my mind that the virus would have multiplied and come back.

44. The impact of Hepatitis C on our family has been varied. We did not tell our other family members straight away, because W and I needed to digest the news first. But we did tell them eventually.

45. With regards to our four children, W and I do not tend to discuss her illness with them that much. I think they do understand something of the illness, but I do not think they have grasped the full impact. They had all grown up and moved away by the time W was diagnosed, so they did not have to see the illness take its toll on W the way that I did.

46. I believe their lack of understanding about Hepatitis C and the way that it has affected us is partly to do with the fact that they do not really want to think about it. W and I also do not always want to talk about it when we see our children and grandchildren. Whenever we see them, it is a happy occasion with an air of normality, so the last thing we want to do is to start discussing Hepatitis C. The children do ask all of the right questions, but I do not think that they properly understand the repercussions of having Hepatitis C because they have never had to live with it in any capacity. Having to explain everything to them is another reason why I do not tend to discuss it with them that much.

47. The illness has also strained W relationship with my mother. My mother just does not understand; she knows W has not been well, but she is unsympathetic and believes W should just "pull herself together". My mother, being from the older generation, has a tougher outlook and just does not understand what W is going through.

48. Moreover, there was such a stigma to overcome when I explained to my mother that W cirrhosis of the liver. As soon as I had mentioned cirrhosis, my mother thought of alcoholics straight away and told me that she thought only alcoholics got cirrhosis. I had to try to explain that W cirrhosis was not because of alcoholism.

49. We have received similar reactions whenever we have had to explain W illness to other people. Their immediate reactions are always the same, asking how W had contracted such a disease. I always think that they could be talking about alcoholism or drug abuse behind our backs.

50. It is wearying to have to explain our situation to others repeatedly. I have now reached a point where I do not feel like I should have to keep explaining ourselves to others. I feel huge sympathy for W as she has to constantly explain how she was infected.

Section 6. Treatment/Care/Support

51. W has never received any form of counselling or psychological support since being diagnosed with Hepatitis C, nor has she experienced any difficulties in accessing treatment as a result of being infected.

Section 7. Financial Assistance

52. I remember that W received financial assistance from the Skipton Fund. She received the Stage 1 lump sum of £20,000 in May 2016, then received the Stage 2 payment of £50,000 shortly afterwards in June 2016 as she had developed cirrhosis. I believe we also received some discretionary top-up payments, although I cannot remember the amount or dates of when these were received.

53. The process of applying for financial assistance from Skipton was very stressful. It felt like it was just one thing after another, which was an unnecessary burden when considering all of the other problems we were already dealing with. W and I had both been working for our entire lives before she became ill, but I still felt very embarrassed to be asking for money. I felt like I was going with a begging bowl. I found the whole experience to be embarrassing and degrading.

Section 8. Other Issues

54. W illness has changed our lives drastically. It should never have happened, and we should have received much better treatment when W was finally diagnosed. We should have been given more

information about everything: the disease we were fighting, the procedures involved and the possible side effects of treatments.

55. There should also have been much more support for affected people such as myself. Seeing W suffer the way that I have has caused me great distress, but I do not have anybody to talk to about it who will fully understand what we are going through. I feel very isolated, but at the same time I believe that I cannot be the only affected partner feeling this way. I hope that affected people can receive more support in the future.

Statement of Truth

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

Signed GRO-B

Dated 2ND JUNE 2019