Witness Name: GRO-B
Statement No.: WITN0815001
Exhibits: None
Dated: 30 April 2019

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 18 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 1978 and my address is known to the Inquiry. I am married with two children, born in 2005 and 2008, and work as GRO-B

2. I intend to speak about my infection with Hepatitis C ("HCV"). In particular, I will speak about the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and my family. I shall also touch upon my mother's infection with Hepatitis C and the impact it had on my life.

Section 2. How Infected

3. I was infected with Hepatitis C in utero when carried by my mother, GRO-B during pregnancy. I understand that my mother has already provided a statement to the Inquiry.

4. My mother was infected with HCV in 1974. My understanding is that she needed to go to hospital as she was suffering from severe septicaemia, and required a blood transfusion whilst she was being treated. I knew the story about my mother's septicaemia and blood transfusion before she was diagnosed with HCV, as she had told me about it when I was growing up.

5. However, my mother had not been diagnosed with HCV when she was pregnant with me, some 4 years later and unknowingly passed it on to me. Neither of us had any physical symptoms of HCV, so there was never any reason to suspect that we were infected.

6. I was diagnosed as Hepatitis C positive in 1993, when I was 15 years old. A couple of years prior to that, my mother had been diagnosed with HCV, but I was too young to realise what that meant. She was a nurse and therefore had been tested for various infections on and off throughout her career, but my mum did not appear to be ill in any way so hearing that she had Hepatitis C was a complete and utter shock.

7. I remember being taken to our local GP surgery for a blood test sometime during 1993. I did not really know what the test was for, but I remember learning within a few weeks that I had tested positive for Hepatitis C. I cannot remember exactly how my mother was told of the results – I think she may have been told over a telephone call – but I recall that she was told without any sugar-coating or sensitivity of the issue. I can only assume that the person giving my mother this information, did not have any understanding of the implications of what they were actually telling her.

8. My mum then told me that I had Hepatitis C. She explained as much as she could of how my infection had come about. It was difficult for me to

comprehend the severity of the situation, because I had always felt absolutely fine. I did not feel any different as a result of finding out that I had Hepatitis C. Moreover, my mother was also in good health as far as I could tell.

9. However, my mother was very upset by the news of my diagnosis, so I deduced from this that the situation was very bad. Her reaction was the thing that frightened me the most, because it told me that my diagnosis was serious. I did not know much about Hepatitis C other than that – I was busy preparing for my GCSEs at school and there was no internet, so I could not research it properly, as I would be able to today.

10. My other memories of the time when I was diagnosed are vague, as it was such a long time ago. My mum took me to Addenbrooke's Hospital in Cambridge to get me on their register, and I remember attending a number subsequent appointments which all tend to merge.

11. I believe that my first appointment at Addenbrooke's was the first time I had ever been inside a hospital waiting room. I remember waiting there with other patients, all of whom looked incredibly unwell. I retain in my mind, a particular image of a young mother and her baby, because they were very yellow. I recall asking my mum as to why they were so yellow. Seeing those very ill people in the waiting room was the first time that the severity of having Hepatitis C really hit me.

12. I do not remember the finer details of my hospital appointments, but the message I received was that I had been infected with HCV through my mother while I was in her womb, and that there was nothing the hospital could do about it. The doctors told my mother and I about the treatments, but they all sounded horrendous and they were not recommended for either of us as we were both otherwise well and healthy. My understanding was that treatment for HCV was in its infancy and still effectively being trialled.

13. I heard about interferon, but I was told that it would make me feel like I had a bad flu for months and months at a time. I was told that I had to get very

ill from Hepatitis C before I would be given the interferon treatment, and the implication was that it would be up to my mother and I to look after ourselves to ensure this did not happen. I also recall that the possibility of a liver transplant was mentioned, and being shocked that I might potentially require such a serious operation.

14. My overarching memory of my appointments at the hospital was that I was told not to tell anyone else that I had Hepatitis C. My mother also told me not to tell anyone else. The rationale was that even if it was accepted by other people that I got the infection from my mother, they might still think that my mum had contracted HCV through some undesirable lifestyle choice rather than through an infected blood transfusion. The general message was that if the news of my mother's infection got out, our lives would collapse because my mother was a district nurse. Therefore, I could not risk telling anybody.

Section 3. Other Infections

15. I do not believe that my mother has received any infection other than HCV as a result of being given infected blood.

16. I do not believe that I have received any infection other than HCV as a result of being infected in utero.

Section 4. Consent

17. I do not believe that I was ever treated or tested without my knowledge or consent, or without being given adequate information.

18. I have given blood a number of times for research purposes, but I have always consented to that.

Section 5. Impact

19. At the time when I was diagnosed, there were no treatments that were appropriate for me. I was seemingly healthy and I was undergoing annual blood tests. For that reason, I resisted having a biopsy for a long time.

20. I believe it was around 2002 when the doctors finally convinced me to have a biopsy at Addenbrooke's. It was a horrible, traumatic experience. My blood pressure dropped hugely so that I kept losing consciousness, and the medical staff had to prop my feet up on the bed to help with my blood pressure. The doctors also thought that I might have sustained internal bleeding, so I had to have a chest x-ray and stay in hospital overnight. I also had a displaced pain in my left shoulder after the biopsy.

21. A few years previously when I was around 17 years old, I had been hospitalised with an incredibly low platelet count. I needed to have a lumber puncture, which was another awful experience as I was only under local anaesthetic and so was awake when I was undergoing this procedure. I also had to stay in hospital overnight on that occasion. I believe that this incident was related to HCV.

22. The biopsy showed that I had mild scarring on my liver. At that point, I was in my twenties and I had never even drunk a drop of alcohol in my life. My diagnosis was when I was fifteen and I was too frightened that it would not help with the condition of my liver. Because the scarring was only mild and I had no other physical symptoms of Hepatitis C, I was not advised to start any course of treatment.

23. The first time I was offered any treatment was relatively recently, in 2016. Even then, I was only offered the treatment because my mum had suddenly been diagnosed with liver cirrhosis in late 2015, and I did not want to be next. I did not want to have to become really ill, or suffer irreversible damage before I could access treatment.

24. When my mother was diagnosed with cirrhosis seemingly out of the blue, I was petrified. Firstly, I was very scared for my mum. She became noticeably unwell in November 2015. She was then offered a 12-week course of Harvoni and some other drugs. The treatment eventually cleared the virus to "undetectable" levels, but the drugs made her feel very poorly throughout the entire period of her treatment.

25. Secondly, I was very worried for myself. Throughout all of the preceding years, my mother and I had both dealt with Hepatitis C together and experienced similar levels of relatively good health. After my mum suddenly got cirrhosis, I worried that I would not be far behind. I thought that perhaps a person could live with Hepatitis C for 30 or 40 years, but then would suffer a sudden downturn in health. Therefore, when my mum cleared the virus in early 2016, I went to Addenbrooke's to ask them to give me the treatment.

26. My hepatology nurse at Addenbrooke's, Tracy, was fantastic. I cannot fault her care at all. I was previously one of the lowest priority patients for the treatment, because I was young and healthy. It did not matter that I had two young children to think about if something did happen to me. Then, after I went to see my nurse Tracy about getting treatment, I strangely jumped to the top of the priority list and was offered Harvoni. I believe that she must have raised the matter for me.

27. I started an 8-week course of Harvoni at the end of June 2016. This course of treatment was 4 weeks shorter than my mother's, and I was only on one drug whereas she was given several. I have never been able to understand why I was only given 8 weeks of treatment instead of 12, although when I asked the hospital about it, they cited differing medical needs for my mother and me.

28. When I was given the Harvoni, I was told that a course of treatment costed £35,000 and that I should not lose the tablets because I would not be able to get any more. I did not need to be told to be grateful for the treatment. However, it was the wrong message to send out because the staff were telling me that I was very fortunate to be having the treatment, when

actually my view was that I was very unlucky to need it. I felt like I was supposed to weigh up my own social worth as to whether I deserved that expensive treatment, possibly at someone else's expense. I don't think I should have been made to feel that way.

29. I was instructed to take the Harvoni tablet every day at the same time. The treatment made me feel awful; I had a permanent headache and constant nausea. I felt like I had a permanent flu. In addition to this, because my treatment period coincided with the school holidays, I had two young children to look after. I also carried on going to work throughout this time, other than a one-week holiday to France, which we had already booked before I started the treatment. Even on holiday, I felt terrible for the entire time.

30. I did not have a very high viral load to begin with, so after only two weeks of the treatment, the virus was classed as undetectable. Then at the end of the eight-week treatment around September 2016, I was again told that the virus was undetectable. However, after my three-month check-up, I received a telephone call casually informing me that the virus had come back. I believe it was around Christmas in 2016 when I found out.

31. I was devastated upon hearing this news. I just stayed in bed that weekend and could not do anything. I felt like I had gone through all the pain of that treatment for nothing. I could not understand why the treatment had not worked for me, because the statistical chance of it not working was very small. I had previously raised questions of what would happen if the treatment was ineffective, but the nurses had always confidently asserted that it would work.

32. Addenbrooke's then started investigating why the treatment had failed for me. The first question was whether I had been taking the treatment properly, and I assured them that I had. They then checked the batch with the drug manufacturer, and the results came back fine. The hospital also could not find anything in my blood tests that would have suggested that I

might not respond to the treatment. After that, the hospital said that there was nothing more they could do.

33. I was incredibly upset. There were no other treatments available at the time, so I just went back to having annual appointments. The hospital staff tried to put a positive twist on it by saying that the treatment had worked for three months, so I had "had a break". But I was worried because the hospital did not know what happened to those for whom the virus comes back – I thought it might return with a vengeance.

34. It was not until April 2018 when the hospital called me to say that a new drug was available on the market. The medication in question was called Vosevi. I started a 12-week course of this treatment on 22 June 2018. Again, I had to take one tablet every day.

35. I felt worse on this treatment than I had on Harvoni. The side effects were similar – tiredness, headaches, the feeling of permanent flu – but much more intense. The only thing that stopped me from feeling sick was eating, so I snacked a lot and put on about a stone in weight, which was unusual for me.

36. I have since completed the treatment, and my three-month check-up in December 2018 came back with the virus undetectable. My next check-up appointment is not until September 2019, and I know that the closer this gets, the more nervous I will become. I am still a bit sceptical as to whether the treatment has really worked on me, just because of my experience with Harvoni. I will not know until September, because I do not have any symptoms of Hepatitis C and have never experienced any. I do not have much confidence in the treatments.

37. My main concern now is that if the virus has come back and I get ill, there is nothing for the hospital to give me. Addenbrooke's have informed me that if my check-up in September is clear, they can discharge me if I wish. I have the option to stay on, which I think I will because I fear that if I come off their

list of patients, I will never be able to get back on it again, and I do not trust that I will not need to.

38. I am also worried about my children. My son is almost 14 and my daughter is 10. I had them both tested for Hepatitis C when they were 6 months old and they did not have it, but I wish to get them checked again just in case. I know the chances of transmission are minuscule, but I need to know that I have not unknowingly infected my children in the last 14 years.

39. This means that I would have to tell my children about my infection – I cannot bring a 14-year-old for a blood test and not explain what it is for. Up until now, I have never told them about HCV because I did not want them to worry. My daughter in particular would be so scared. They were both already quite worried when I was taking the tablets for treatment, because I was not myself.

40. With regards to the risk of infection to my husband, no one has ever mentioned to me that I might have passed the infection on to him or that he should be tested. I was 15 when I first met my husband, and had only been diagnosed with HCV about 6 months prior. I think I told him about my infection almost straight away, and he has always been completely fine with it. I think he would refuse if I asked him to be tested for Hepatitis C – I believe that he would rather not know.

41. I consider myself to be relatively lucky, because I have never suffered any physical symptoms of infection with Hepatitis C. This is why it was such a shock to hear that I had Hepatitis C – I had always felt perfectly healthy. Even now, when I have apparently cleared the virus, I do not feel any different to how I was when I was infected.

42. Nevertheless, the infection has had a significant impact on my life. I feel that I have been treated differently for various medical procedures because of my infected status.

43. On one occasion, a consultant refused to treat me until I had my platelets checked when he saw on my medical notes that I had HCV. I also attended a dental appointment where the hygienist fully masked and robed herself up before attending to me. She was not even going to be conducting any invasive procedures, so seeing her like that made me feel very contagious. At least this was still better than my mother, who was refused treatment outright by one dentist after finding out that she had Hepatitis C.

44. I was put under the care of a consultant when I was pregnant with my children, due to the fact that I had Hepatitis C. This was supposed to ensure better care, but it did not. I had obstetric cholestasis during pregnancy, a condition related to the liver. I asked the consultant if it was because I had Hepatitis C, and his only response was "I don't think so". The lack of definitive answer was hugely frustrating and was not what I expected from a consultant.

45. During my childbirths, the hospital put big yellow stickers saying "risk of infection" on all of my medical notes. I also recall these stickers being on my files when I was younger. It obviously did not make me feel great, but it was just one of those things I had to deal with.

46. I suffered from post-natal depression after the births of both of my children. I was particularly affected after the birth of my first child; I felt a strong weight of responsibility that I had to keep myself alive for this baby. It completely brought my mood down. I also worried for the first six months that I might have passed the infection on to my children. I knew the chances were small, but it had happened in my case. I further worried about the potential effect on my mum. She already felt unjustifiably guilty about passing the infection on to me; she would have felt even worse if it had been passed down another generation.

47. Despite my depression, the doctors did not dare to give me antidepressants because of the potential effect they could have on my liver. There were several other things that hit a "dead end" because of the HCV. For example,

I was anaemic at one point but I could not take iron tablets due to having Hepatitis C. That was it; I was never offered alternatives.

48. Now, anything minor that happens to me in relation to my health causes concern, because I worry that it is related to Hepatitis C. I am scared that the doctors will suddenly find something wrong with me, which could indicate a sudden downturn in my health, due to HCV.

49. I think that for my whole life, since finding out about my infection I have operated on a lower level of happiness than everyone else. The fear that my health could suddenly deteriorate is the reason why I have not liked to stray too far from home. I was not confident enough to travel and it has only been in the last two or three years that we went on holiday abroad. When my children were young, we would only holiday in England. Now, we have still only been to France and Spain. I was also scared of catching Hepatitis A in another country, in case the combination would prove fatal. For me, it has been a matter of confidence.

50. As I have mentioned above, it was instilled into me since I was 15 years old that I could not tell anyone about my infection, or my mother's. I knew that this was because of the stigma associated with Hepatitis C, and the repercussions it could have for my mum in her job, even though she was never putting anyone she looked after at risk of infection.

51. Consequently, I have friends who I have known my entire life, who have no idea that I have Hepatitis C. I could not tell any of them, not even my best friend, in case they told their mums and word got around. It has put a barrier on my friendships, even with my very best friend. I could not be completely honest with her about what has become such a big part of my life. I was undergoing treatment for Hepatitis C the year that we both turned 40. Because I was suffering badly from the side effects, I could not go to her 40th birthday party. At the same time, I could not tell her why I could not go, so I had to make up an excuse. I felt awful.

52. The fact that I have had to keep my infection secret has left me feeling disingenuous in my closest friendships, and unable to explain my emotional reactions to certain things. When my mum became unwell, it also meant that I could not explain to my friends what was wrong with her. Not being able to tell anyone and share my experiences has been very difficult.

53. I am now in the position where I have finished my treatment and hopefully cleared the virus that I have been living with my entire life, but now I do not know how I can explain all of this history to my best and oldest friend. How can I tell my dearest friend that I had been dealing with Hepatitis C the entire time, and never told her about it before? I do not know how to deal with that.

54. Only a handful of people – perhaps six – were aware of my infection. I had to inform a couple of people at work in case I had an accident in the workplace, as any paramedics treating me would need to be aware of my infection. But generally, not being able to talk to others about it was one of the hardest things about living with Hepatitis C.

55. My infection also had a massive impact on my social life. Because I found out at 15 that I was infected, I never drank any alcohol. Not being able to drink was actually a big factor as to why I did not go to university, despite doing well in my A Levels. I was scared of moving too far away from home in case I fell ill, but also I did not want to go to university and be the person who never drank. I was young, and peer pressure really affected me then. If I knew my friends were going on a big drinking night out, I just would not go because I would not be able to join in. This may not seem serious but when you are a young adult, there is a natural pull to be part of a group and to join in. The fact that I couldn't made me feel different and in some ways isolated that I couldn't involve myself fully like everyone else.

56. Even as an adult, I sometimes feel judged for not drinking alcohol. In my working environment, my colleagues go out for lunch for a drink, or take clients for a drink, or have work nights out and get very drunk. People think it is weird that I never drink. I usually come up with some excuse, such as

saying that I am the designated driver. As I have grown older, I do not care as much what other people think, but I feel like I have missed out on being able to fully enjoy a social life because of my infection.

57. In relation to financial effects of infection, I have fortunately never had to give up work because I was feeling too ill. Further, being in my job as [redacted] my colleague was able to find someone who would give me a life insurance policy for the rest of my life. Nevertheless, I had to pay a premium of £25 per month. This contrasted with my husband's payment of £6 per month, despite the fact that he was a smoker at the time. I have also never joined the BUPA scheme at work, simply because they would not have covered me for HCV, the thing I would probably need it most for.

Section 6. Treatment/Care/Support

58. My mother and I were left to look after ourselves for many years without treatment. I understand that this was because better drugs had not yet been developed, but I still felt like the fact we had to wait so long was disgraceful. Particularly Mum who had to get cirrhosis before getting treatment. Maybe if she had had it before, she may have avoided the damage to her liver.

59. However, the most deficient part of the treatment for me is that we have never been offered any psychological help. Dealing with the psychological impact of infection has been the hardest part for me, but the possibility of support was never mentioned. Even when I have been visibly upset at appointments, I was never offered any counselling or psychological support.

Section 7. Financial Assistance

60. I received financial assistance from the Skipton Fund, which has now been replaced by the England Infected Blood Support Scheme ("EIBSS").

61. I got the Stage 1 payment of £20,000 in 2001. However, I did not spend that money until last year when we moved house, because I was too afraid. I kept the money safe, in case something happened to me that meant I could not work, and my family would need to live on that.

62. I did not receive anything else from Skipton until they started paying an annual amount of £3,500, which I received in quarterly instalments. Then the EIBSS took over the scheme and introduced a special category mechanism. I applied for it on the basis of the impact on my mental wellbeing, so now I have been receiving a monthly payment of £1536 for just over a year.

63. I am very grateful that I receive these payments, but I find myself unable to spend the money because I do not trust the payments not to suddenly stop. I also do not know when I might need the money. I think a big part my holding back from spending the money is that I still cannot be confident that my treatment has worked.

64. Since I work in the GRO-B I am also somewhat sceptical about why the government is handing out this money. I do not believe that they would do it if there was no fault on their part, regardless of their labelling it as an ex-gratia payment. I think there is fault there. I suspect they might be paying through the EIBSS to satisfy people just enough not to take them to court and get a lot more money.

Section 8. Other Issues

65. The main thing that I want to come out from this Inquiry is some acknowledgement and recognition from the government that there was fault on their part to allow this scandal to happen. I believe that the setting up of the Skipton Fund is a clear indication that there was an organisational failure at some point. I would therefore like an acknowledgement from the authorities that infected blood was something they were aware of at the time, and I want them to recognise the impact it has had on myself and others like me.

66. Some acknowledgement as to fault would enable me to live a more open life. I would like to be able to tell my friend, because keeping this a secret for my whole life has been very upsetting. I strongly hope that nothing like this ever happens again.

Statement of Truth

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

Signed GRO-B

Dated 30/4/19.