ANONYMOUS

Witness Name: GRO-B
Statement No. WITN3160001
Exhibits: WITN3160002 GRO-B
Dated: October 2019 20/10/19

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

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

Section 1: Introduction

1. My name is GRO-B My date of birth is GRO-B 1941 and I reside at GRO-B I married my husband, GRO-B, on GRO-B 1962 and we have two children. I had one younger brother who unfortunately died a few hours after his birth. I did not have any other siblings.

2. I was working as a payroll clerk until 1992, when I was diagnosed with Hepatitis C and my symptoms meant I could no longer work. I make this statement based on my recollection of events, as I do not yet have access to my medical records.

Section 2: How infected

Haemophilia

3. I have haemophilia B. I was not diagnosed as a haemophiliac until around 1980. I was 40 years old at the time. Prior to that I had not received any blood products for bleeding, as I had not been diagnosed with haemophilia B. However, I do

recall being given tablets before tooth extractions, as I bled more than normal, and having a blood transfusion for a tonsillectomy when I was 11 years old.

4. Before my diagnosis, the only time I have experienced additional bleeding has been when I have had teeth extracted. When I had a tooth removed, I would bleed continuously and then it would stop within a day. I would think I had finished bleeding, but then a day later the bleeding would start again. That is the main difference between haemophilia A and haemophilia B. My blood does clot but the clot then breaks up and the bleeding starts again. In addition, I only bleed more than average when something is pulled out or is torn, such as with tooth extraction.

5. I had two daughters, born in GRO-B 1963 and GRO-B 1968, and I did not need any blood product cover for either of those births; I just bled a little bit more than you would normally expect. At the time, the doctors did not know why I bled more than expected. The doctors were able to control the bleeding and I did not need any blood products. I had my first child in hospital and I had the second child at home.

6. I had led a normal life up until being diagnosed with haemophilia and I found I only bled a little more than my husband. The doctors just told me that I was "a bleeder" and I did not think I could do anything about that.

7. I had two teeth removed in 1972 and I had intermittent bleeding. I was then referred to Dr Ibbotson at the Royal Stoke Hospital ("RSH") on 14 March 1980 and he tested me for haemophilia when I was admitted for a tooth extraction in July that year. When I was diagnosed with haemophilia, I was not given any advice about the condition. Dr Ibbotson seemed thrilled that somebody in GRO-B GRO-B had haemophilia B. It is also commonly known as the "Christmas Disease" because it was diagnosed on Christmas Island.

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8. Following my diagnosis with haemophilia, Dr Ibbotson ensured my mother was also tested. She has 48% clotting level. This means she is a carrier of haemophilia although she has a relatively high clotting level. My clotting level is around 22%. It made sense that my mother was a carrier and she had passed haemophilia onto me. It may also explain why my brother died when he was a few hours old. Nobody knew what had caused his death and there were no tests for haemophilia back then. One of my daughters is also a haemophilia carrier but the other is not. The daughter that is a haemophilia carrier has had two sons but neither of them have haemophilia.

9. I have access to the haemophilia nurse if I need any teeth removing or if I have any other medical concern but generally I do not need treatment apart from this. I have mainly needed treatment for my Hepatitis C. I have routine appointments once every 12 months to review and check my clotting level. Knowing my clotting level has been useful in case I ever needed an operation, although thankfully this has not been necessary so far.

Treatment with blood products

10. In 1980 my dentist informed me that I needed two teeth extracting, and he said he was not willing to remove the teeth in his surgery as I had told him I had a history of severe bleeding. Therefore, I was sent to the RSH for this dental treatment. Initially I was told by the dentist that I needed two teeth to be removed, but upon examination at the RSH by Mr Leopard, he determined those two teeth were satisfactory, although another four needed to be removed. I have not been to a NHS dentist for tooth extraction since this incident; I have always gone to the hospital.

11. The tooth extraction took place on 22 July 1980. During that tooth extraction I received Factor IX product. This was the first time I had received blood products. On 31 July 1995, an expert report was prepared by Dr Colvin, Consultant Haematologist, who had the benefit of access to my medical records [Exhibit

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WITN3160002] ("the Report"). This was arranged through my solicitor. The Report confirms *"there is a record that 2,100iu of concentrate was given on 23 July 1980, plus tranexamic acid and no abnormal bleeding occurred."*

12. At the time, I did not know I was being given a blood product, as it was a white liquid and I was not told what it was. I had believed it was a liquid form of the tablets I had previously been given to control bleeding. I was never told there might be a risk of infection from receiving Factor IX product. Following the tooth extraction, they plugged the socket and stitched it, as a precaution.

13. On 14 August 1987 I had a dilation and curettage ("D&C") procedure because I had gynaecological issues. I went to the RSH for this procedure and I received Factor IX product for the second time. I had not received any blood products between 1980 and 1987. At the time, I was told that Factor IX was a product which would help my blood to clot, and I was told I needed to have it before I had the D&C procedure.

14. At the time I went into the RSH for this procedure, HIV was a prevalent topic in the media. Consequently, I told the doctors I did not want Factor IX products, as I thought there was a risk of being infected, from what I had seen in the media. I asked the doctors about the risk of being infected with HIV and they told me there was a 99.9% chance I would not contract anything. At the time, I was not aware of Hepatitis C, and so it was HIV that I was concerned about. I was told everything would be alright, but I still did not want to have Factor IX. I told the doctor that I did not need Factor IX for the D&C procedure, as I only bleed more than an average person when something is pulled or torn, for example teeth extraction and major operations.

15. Prior to the procedure, a doctor came in to give me my pre-medication at around 13.15 hours. The procedure was scheduled for 14.00 hours. At around 13.45 hours, I was told the doctor scheduled to perform the procedure, Mr Menon,

indicated he would not do it unless I took the Factor IX. By that time, I was quite drowsy from the pre medication and I had no real option; they gave me Factor IX despite my previous refusal.

16. I do not believe I was given a real choice about whether to have Factor IX for the D&C procedure. I had refused it, and the doctors had waited until I was drowsy before giving the treatment to me anyway. According to the Report, *"there is a record that 1,290iu of heat treated Factor IX concentrate was given. No abnormal bleeding occurred."*

17. I reacted very badly to the Factor IX I was given in 1987 and I was unwell for several weeks. My energy levels fell and I was frequently sweating; my health was deteriorating. I phoned Dr Ibbotson for an urgent appointment and he told me it could be *"a Hepatitis attack",* even though I was not jaundiced. He did not mention this would be a permanent condition; he made it sound as though it would go away. He may have called it "Non-A Non-B Hepatitis". The Report, based on my medical records, confirms this [WITNXXXX002]. I was not tested for any type of Hepatitis at the time so I do not know what made him think the symptoms could be caused by Hepatitis. Dr Ibbotson had been on holiday when I had my D&C procedure. When he returned he told me that had he been available at the time of my procedure, he would have said it could go ahead without Factor IX cover.

18. After experiencing the symptoms for a few weeks, as I was not feeling better, I went to my GP. He told me it was probably a virus, but he did not say which one. I was not tested for any viruses at the time.

19. I had two weeks off work. I was only 47 years old and I was experiencing chronic fatigue, however when I went to the GP in relation to this, I was told it could be the menopause. I was only given those options; it was either a virus or my age. I thought to myself, *"that's a load of rubbish."* Unfortunately, I never got anywhere

with the GP after that. The symptoms continued and I did not have any tests until 1992.

20. My husband recalls my symptoms at that time well; I was not able to do anything around the house. We had two dogs at the time and I used to love walking in the fresh air. After the treatment in 1987, when my health began to deteriorate, I would agree to go for a walk with my husband and the dogs. I would put my shoes on, but I would only walk 20 yards when my face would go pale, I would begin sweating and I would have to go home. My husband had to do most of the work around the home and he still does.

21. Since 1987, I have continued to have factor products for teeth extractions. Dentists will not remove my teeth unless I have factor cover. Now I would have recombinant factor (a synthetic product) if I required an operation or a tooth extraction.

Diagnosis with Hepatitis C

22. I was not informed that I had contracted Hepatitis C until 1992, nearly ten years later, when I was 50 years old. This was despite repeatedly visiting the GP as I was experiencing symptoms, such as very low energy levels (which I explain in detail in paragraph 17 above).

23. In August 1992, I had a regular appointment with Dr Ibbotson. I was still experiencing extreme fatigue. I explained the symptoms to him and he said, *"oh, we better take some tests then."* He took blood tests on that day and I did not have to wait long for the results.

24. I went back to see Dr Ibbotson on 7 September 1992 for the results and he said, *"I'm glad to tell you, you don't have HIV, you don't have Hepatitis B but I'm sorry to tell you, you have Hepatitis C."* I was told very bluntly. My husband was not

with me at the appointment because Dr Ibbotson did not indicate that I should be expecting bad news.

25. I asked Dr Ibbotson what having Hepatitis C meant and he said, *"oh you're another one that's going to sue me."* He said this in a jokey way but given the topic of conversation, I did not think that was appropriate. I had gotten to know Dr Ibbotson well over the years he was treating me and he did have a jokey manner. However, I still do not think the way in which I was told I had Hepatitis C was appropriate.

26. I asked for some more information about Hepatitis C and he said he did not know much about it. I was told that the virus was attacking my liver and then when my liver was destroyed, there would be nothing more they could do. I was told that I could not have a liver transplant because I was already too old. He did ask if I had any questions, but I felt so shocked I only asked a few.

27. I was in a total state of shock. I went home and told my husband that I had contracted Hepatitis C. I told my husband that I did not have very much information. I recall at some point the Hepatitis nurse gave me a booklet on Hepatitis C but that was at least a few years after this. In terms of the risk of transmitting Hepatitis C, we had to find out information ourselves and I was not told anything by a doctor. If I did not have a husband that was so amazing, then I do not know what I would have done.

28. Shortly after my diagnosis, later in September 1992, I had to finish work permanently. I had already been off work with ill health for the three months prior to this. I could not concentrate on anything; the diagnosis completely changed my life. I did not tell my employer that I had Hepatitis C; they knew I was ill and I told them I had a virus and could no longer work. I did not think there was any need to tell them anything more specific. They would not have known what

Hepatitis C was at the time; I could not understand it myself. I have not been able to go back to work since.

29. I understand it was during the tooth extraction in 1980, when I was given Factor IX, that I contracted Hepatitis C. The Report confirms *"there is now no doubt that the treatment given in 1980 would have transmitted Non-A Non-B Hepatitis (now Hepatitis C) but there was no agreement at the time that all patients should be warned of the risk (which was not yet fully known)... the illness of 1987 nine days after D&C cannot be confirmed as being due to acute attack of Hepatitis and I have no doubt that if frozen samples are available it would be possible to demonstrate that Hepatitis C infection took place in 1980."* Although we instructed a solicitor we did not get very far with bringing a claim, as not much was known about Hepatitis C at the time.

Section 3: Other infections

30. As far as I am aware, I have not contracted any other infections as a result of contaminated blood products. The Report confirms I had a Hepatitis B vaccination in 1991.

31. Not long after I was diagnosed with Hepatitis C, in around 1993, I had a scare with vCJD which is commonly known as "mad cow disease". I had heard that the RSH was checking which patients had received plasma which would put them at risk of contracting vCJD. I was told the RSH would write to us if we were at risk. I, along with other haemophiliacs I knew, expected to receive a letter but we have not received anything.

Section 4: Consent

32. As I have referred to at paragraphs 15 and 16 above, I did not consent to receiving Factor IX products either during the tooth extraction in 1980 or during my D&C

procedure in 1987. In 1980 I was not told anything about the white liquid I was given, neither what it was nor any risks of taking it. In 1987 I was aware that HIV could be contracted through blood products, which was often reported by the media, and I had specifically said I did not want Factor IX products. Unfortunately, those wishes were overridden, as I was approached in a drowsy state just before the procedure, and I was given Factor IX for the second time.

33. I was not aware that I wold be tested for Hepatitis C when I went for blood tests in 1992. I did not know Hepatitis C was a possibility. According to the Report, Dr Ibbotson completed a HIV test in 1985 and it was negative. I cannot recall being told about the results of the HIV test in 1985; I believe I was told in 1992.

Section 5: Impact

Psychological impact on me

34. I was very fortunate that I have strong faith, which I think has helped me come to terms with my diagnosis with Hepatitis C and deal with the subsequent treatment. I also do not drink or smoke and I think that has helped me too.

35. After my diagnosis, I joined a group of people with haemophilia, many of whom had contracted Hepatitis C, called the GRO-B ("MHG"). I found the MHG very helpful, because they provided a lot of information. I found some of the MHG meetings upsetting, as there were so many young people there. Some of those young people could not get mortgages and they had young children. I was over 50 years old at the time and I felt I had had my life, but they had not yet had theirs. I was sad for those other people with young families. Our two daughters had already grown up. I felt that other people were going through far more than I was.

Physical impact on me

36. Following my diagnosis in 1992, I was not managing my symptoms very well. I had one daughter living at home and another living away. The daughter that lived

away from home did not see me much, although she knew I had Hepatitis C. The daughter at home, and my husband, saw more of the effects of Hepatitis C on me and I became a fraction of my former self.

37. I was not offered any treatment until around 1995, three years after my diagnosis. I was offered Interferon treatment which would last for 12 months. From my involvement with the MHG, I knew that Interferon had made people very unwell. I asked the Lord what I should do and he answered. I decided not to have the treatment.

38. In around 1998, I was under the care of Dr Brind, Liver Consultant, at the RSH. She had seen that I had never had treatment for my Hepatitis C. She told me that the Interferon treatment that I was offered in 1995 would not have touched the viral load that I had; I had a very high viral load. Unfortunately, she said there was no alternative treatment that would clear my Hepatitis C.

39. Then, at the end of 2016 or start of 2017, I was offered treatment with the combined drugs of Interferon and Ribavirin. The treatment was only going to be offered to a handful of people at the RSH. The Hepatitis nurse called me and asked if I wanted my name to be put down. She said to me, *"the way you contracted Hepatitis C, you deserve to be put forward."* I thought they would not accept me for the drug trial due to my age. However, they did put me forward to receive the treatment.

40. I had to take eight tablets with the treatment. I struggle to take tablets and so I did not find this treatment regime easy. I would take the treatment in the morning and within an hour I would become extremely unwell. I had horrible side effects; it was really terrible. I had always had very good sleep but I was losing sleep whilst on this treatment. I was also jaundiced and my liver function tests rocketed. This caused great concern at the RSH. I was grateful the RSH had agreed to let

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me have the treatment, so I was determined to take it, but it was a terrible drug combination. My life just stopped during this treatment and I felt like I was dying.

41. I began treatment over the Christmas period and I really thought I was dying. I had never experienced anything like it. I felt like the treatment was attacking every organ in my body. I rang the Hepatitis nurse and I told her how ill I was. The nurse was very concerned. I was not admitted to hospital at this time but I was told that if my liver function did not improve I might need to go to the Queen Elizabeth Hospital in Birmingham and I believe they were consulted about my condition. At the end of four weeks of treatment my liver function tests had improved a little bit, so I was told I was able to carry on with the treatment, but I did not want to and so the treatment did not continue.

42. I have felt a sense of peace since we became Christians and I think that sustained us psychologically throughout this treatment. I made peace with my decision to stop the treatment.

43. I still wonder whether this treatment has had a permanent effect on me. My liver function spiralled out of control at the start. I believe the treatment upset my whole system. I was angry that Interferon and Ribavirin had cleared the virus for some people, but it had only made me more unwell. Even now I have no energy, although I appreciate I am now older than when I started treatment.

44. In December 2017 or January 2018, I was offered a new treatment for Hepatitis C called Harvoni. I was told the treatment would last three months and I would have to take one tablet a day. I was told the side effects would be minimal.

45. The Harvoni treatment was okay. I had read about the side effects of taking Harvoni, such as psychotic symptoms, but I did not really experience any of them. I was nauseous for a couple of hours after taking the treatment but nothing

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continuous. The only ongoing problem I have had is that my stomach is bloated up now, which I understand can be a side effect of this treatment.

46. Following the treatment, I was informed I had cleared the virus in May 2018 and the nurse discharged me. I was elated that Hepatitis C was not attacking my liver anymore. I am so relieved I do not have to think about other people contracting Hepatitis C anymore, particularly around GRO-B and my family. For example, if I was ever cooking and I cut myself and I was bleeding, I always thought to myself, *"Hepatitis C lives within that blood."* I was always very careful about cleaning up blood.

47. However, despite clearing the virus, my health has never really improved much. Recently, I rang Dr Brind to ask if there was a chance I had liver fibrosis, as one of the nurses had mentioned this to me. I am waiting for an appointment, which should come through in August or September 2019. I consider that the RSH should have continued to review me, perhaps every 12 months, even though I have cleared the virus.

Impact on family

48. At the time of my diagnosis in 1992, one of my daughters was living with us and she was working at GRO-B at the time. She was very worried about me and it affected her tremendously. She always noticed that it would take a while for me to get up in the morning. She saw all of the side effects of Hepatitis C and the treatments. She was the one that encouraged me to take the second treatment, Harvoni. She had read that it had a good record of success in Canada.

49. My whole family were very worried about me. The daughter living away at the time knew that I had Hepatitis C, but she did not witness the daily effects of this. My mother knew something was drastically wrong, but she passed away and I never told her about the diagnosis.

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Impact on employment and finances

50. Prior to my diagnosis, I had been working part time. I had moved jobs to work at [redacted] University in 1990. I had never earned enough to pay national insurance but I was earning a good wage for two and a half days a week. Just before I was due to finish work, I began paying full national insurance and I was going to go onto the pension scheme. I had even signed the forms to join the pension scheme but then I had to finish work due to my deteriorating health.

51. I had to stop work in September 1992, having already had the previous three months off work. Unfortunately, at the same time my husband had been made redundant.

52. I tried to apply for benefits but because I was not paying full national insurance at the time, I was advised I could not claim benefits. In any event, I have never wanted to claim anything that I was not entitled to. It felt demeaning to fill in forms about how far I could walk, when that depended on how I was feeling on the specific day. It is human nature to think that unless you have a walking stick then you must be fit, well and able to walk. People do not recognise an internal affliction.

53. [redacted] received a redundancy payment around this time which helped. When I finished work, we did struggle with money. I thought that I would be able to go back to work after I had received treatment and felt better, but that never happened.

54. [redacted] is now receiving a pension and I have a small pension from his pension.. I do not have a pension of my own, as a result of being unable to work due to my health.

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Section 6: Treatment, care and support

55. I received all of my medical treatment at the RSH. I was never offered any counselling in respect of either my diagnosis or the treatment for Hepatitis C. I would have accepted it had it been offered.

Section 7: Financial Assistance

56. A few years ago, a member of The Haemophilia Society told me that I could obtain financial assistance from the Government because I had contracted Hepatitis C. I received an interim payment of £20,000 from the Skipton Fund. I cannot remember ever making an application for it or whether I had to sign anything. I believe The Haemophilia Society had sent the papers to me because there was a chance I would be able to claim something.

57. I also began receiving regular payments in November 2016. From November 2016 to June 2017 I received £208.33 a month. From 20 June 2017 to March 2018 I received £257.50 a month. After that, I recall I had to fill in a form to say how much income we received between us, to see whether we were eligible to receive a top-up payment. On 27 August 2018 I began to receive top-up payments due to low income. This amounted to £362 per month, which was back paid to April 2018 in a lump sum of £1,448.

58. Completing the forms felt like going "cap-in-hand" to the Government. I had to provide lots of financial information that I felt was our private business. Finances were a concern for us, so we had no choice but to complete the forms. I am aware the Skipton Fund then transferred then to EIBSS.

59. I have also received a winter fuel allowance from EIBSS for the last two years. I was told these were one off payments. This year the winter fuel allowance was £531.

60. This year the monthly payments from EIBSS have increased a lot and have been backdated to April 2019. Since 3 May 2019 I have been receiving £1,538.17 a month. This includes an income top-up payment.

61. I just feel that after all these years this is too little too late. Before this, between us we only received around £458 a month from GRO-B work pension plus £129.68 a week for GRO-B state pension. I then received £72.07 from GRO-B pension at work. I am grateful for the payments now though, as they are helping.

Stigma

62. I did not tell my neighbours about my diagnosis. I have told friends and family about my diagnosis with Hepatitis C. I told GRO-B sister and both my daughters. I did not tell anybody else so I do not think I experienced stigma. I got on with my life; I got up when I could, I put makeup on, did my hair and everybody thought everything was fine.

Obstacles to treatment

63. I had difficulty obtaining dental treatment. No NHS dentists actually refused to treat me but they were being very difficult. They also felt very apprehensive, particularly if they had to give me an injection. I decided I would just not go for dental treatment, until Dr Ibbotson found out and contacted Birmingham Dental Hospital on my behalf. I have been receiving dental treatment from them since then, although it has phased out over the last few years. I now go to a NHS dentist for fillings and routine treatment but I would still go to the RSH for any tooth extractions needed.

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Section 8: Other Issues

64. Hepatitis C had devastated my life. I always used to think to myself "how do you tell people?". People think you are not working because you are being idle. I cannot do the things I used to do and enjoy like gardening. I have had to let my house go because I do not have the energy to maintain it to the standard I would have wanted to.

65. I pray for justice from this Inquiry. Contaminated blood has devastated so many people's lives and I am very grateful to still be here after 39 years. It is too late for me but I do not want it to happen ever again. I believe the Government was lackadaisical with haemophiliacs and they could do it to another group of people in the future just as easily. I do not want anybody else to have to go through this.

66. It could have taken my marriage away and for many it did; I was very fortunate. Some young people diagnosed with HIV or Hepatitis C could not get mortgages. I was fortunate because I had finished paying my mortgage by the time I was diagnosed. We have enjoyed our life but we are always thinking of others, especially those infected that have children. I do not know how we would have coped had the children been younger. It should never have happened. It is not just about me; it is about all the other people that have also been infected or affected.

Statement of Truth

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

Signed ...GRO-B...............

Dated ....20/10/19.......................