ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN3768001
Exhibits: **WITN3768002-5**
Dated: 29 April 2020

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 26 September 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B GRO-B and my address is known to the Inquiry. I am now retired and was formerly an office worker in the banking and education sector.

2. I intend to speak about my experience of being infected with Hepatitis C (HCV) from a blood transfusion I received. In particular, I will speak about the nature my illness, how the illness and its treatment affected me and my family, and impact it had on myself and my family and our lives together.

3. I confirm that I am not legally represented. I would like to seek anonymity on the basis that I reside in a close-knit community where no one is aware of my status and it will protect the privacy of myself and my immediate family.

Section 2. How Infected

4. In GRO-B we were living in Liverpool and I was 32 weeks pregnant. One day I was at home and I suddenly haemorrhaged. I was rushed in by flying squad to the GRO-B Hospital, as it was called then, where they discovered that the placenta had ruptured – it had come away and smothered the baby. The baby had no heartbeat.

5. I went into labour which lasted 7 hours, and my baby was still-born. I had had a massive haemorrhage, and I vaguely remember having a blood transfusion. My memory of that time is quite foggy, hazy. It was obviously a traumatic period for me and I would likely have been sedated to some extent due to the procedures I underwent. The exhibit marked WITN3768002, being correspondence between my Doctor and GRO-B records the fact that I was transfused in 1977 and that I am not in any other risk group of being infected with Hepatitis.

6. No one said anything about any of the risks of receiving a blood transfusion at the time, and nor would I have thought to ask. Not only due to my condition but it wasn't the 'done' thing then. You trusted doctors and hospitals. They were there to take care of you. My husband was kept separate from me, I presume because of my medical state, so he was unable to ask any questions either After several days of being in hospital, where I was in ward full of new-born babies, I discharged myself.

7. As a result of the transfusions, I was infected with Hepatitis C (HCV) genotype 1B, but of course I didn't find out about the infection until much later.

8. I have never had any other surgeries or operations nor at any other time received a blood transfusion. I am happily married and have never been sexually promiscuous nor a user of intravenous drugs. I do not have any tattoos or body piercings.

9. In 1997 our social conscience had led us to decide that we ought to donate blood, we went to up to the village where we all queued waiting in line to give blood. As part of the process of taking blood they took a finger-prick test to check whether you were eligible to give blood. At the time I had no inkling whatsoever that there would be some sort of problem.

10. Two weeks later I receive a letter in the post. It didn't say exactly what the issue was, but that there were some abnormalities in my blood test results and that they needed to speak to me urgently – I think that was from the Blood Transfusion Service.

11. I went to my GP where they were able to find out the test results. At the time my GP was GRO-B and that's when we found out it was HCV. We didn't know anything about Hepatitis, nothing at all. GRO-B admitted she didn't know much about it herself, in fact she actually later attended a lecture on HCV. I do not believe she gave me precautions to take then. She certainly did not give me information on how to manage the virus and what affect it may have on my life going forward.

12. I was referred to a specialist GRO-B at the Queen Elizabeth Hospital. It was there where we were given basic precautions, they explained it was a blood borne virus and that we shouldn't share toothbrushes and so on. Again, we weren't given very much information, other than it was blood to blood. It was a bit airy fairy to be honest.

13. In the following weeks and months there were many appointments, toing and froing. GRO-B gave me a lot more detail on the virus, the various types that existed, how serious it was, and he explained why a

liver biopsy was important – I may have liver damage due to the virus lying undetected for so long in my system - so I agreed to have one done.

14. The biopsy was very invasive. It was very painful and uncomfortable. At the time, I didn't think the trauma caused by the procedure outweighed the benefits of having it done. I was never offered an MRI or a scan of the liver, and I never thought to ask. I've only ever had 1 biopsy.

15. GRO-B also explained that there was a treatment available, but it wasn't suggested that I start the treatment, because I didn't have any of the obvious symptoms that were common for HCV. It was concluded that they will monitor me and reassess in 6 months' time – it was a case of wait and see. 6 months went by, then another 6 months, then the checks became annual.

Section 3. Other Infections

16. I do not believe that I have been infected with any viruses other than HCV. However, I know there is a link between the treatment I received for the infection and thyroid problems, and I believe that my treatment that was supposed to clear my HCV caused damage to my thyroid. The HCV may have aggravated this as it is an autoimmune disease and attacks the immune system making you more vulnerable.

Section 4. Consent

17. I have always consented to the tests that have been carried out on me. I do not know if I have been tested for HIV or vCJD. I was never told that I was going to be tested for either of these.

18. Albeit I didn't explicitly consent to being tested for HCV when I went to donate blood, it was probably covered on the paperwork that I completed and I am grateful for that. Thank goodness I went to do my social duty, otherwise I probably wouldn't have known.

Section 5. Impact

19. As I did not have the typical physical symptoms that are associated with HCV, a lot of the impact, well the physical impact from the HCV stemmed from the treatment that I received in 2006 rather than the infection itself.

20. I had two children after receiving the transfusion, and they could have been infected with HCV as I was undiagnosed at the time. I was unaware of the risk that they were exposed to and that they could have been infected. The mental anguish caused by the realisation that you could have inadvertently put your kid's lives at risk is too great to put into words.

21. My husband found it very difficult to get his head around everything that had happened, that I was infected by the transfusion, and how he had to support me when I was going through the treatment.

22. Both my daughters struggled knowing that their mother, who had suffered and dealt with GRO-B from an early age, was suffering from another illness that posed a serious threat to her health and well-being and on top of everything else it was something that could have been avoided.

23. The psychological impact is and always has been ever since the diagnosis, an ever present in our lives. HCV at that time was seen as the slightly lesser evil to HIV. When we found out, my younger daughter was still living at home, so it, and the emotional impact, was a very real presence for her too.

24. If I hadn't known, psychologically it would have made a hell of a difference because once you know, it is always there, in the back of your mind, influencing what you say and do. You always have to be careful, I never tell anyone about it, only my family know.

25. Stigma at that time was an issue, so I resolved no one else would know. You do feel unclean, dirty. The fact that something is wrong with you is always there. Even my parents never knew. Can you imagine having to keep such a secret from your own parents? My mum lived until she was 93, a few years ago, and my father lived until he was 99. I just couldn't put anything else on them, I felt it would be unfair asking them to deal with all the consequences so we kept it from them.

26. I felt the medical profession was very matter of fact about the infection, there was very little compassion shown. I was never offered any counselling to help me deal with the psychological impact of the actual infection nor the later side effects of the treatment.

27. In terms of treatment of HCV, In February 2006 I was transferred to a GRO-B GRO-B in Stoke because she had been doing a clinic in Birmingham, where I had been many times, and she had now opened a clinic in Stoke. It was whilst I was under this clinic in Stoke that the subject of treatment was raised and this time it was recommended that I start it – it was a combination of pegylated interferon and ribavirin.

28. I was apprehensive about beginning the treatment. My medical records note "pt very apprehensive about starting treatment…pt reassured as much as possible". See Exhibit WITN3768003 an extract from GRO-B s notes.

29. Something that stuck in my mind from that time was a comment from one of the nurses. When I wasn't sure about whether I should start the treatment, she said to me, "well do you want to live long enough to see your grandchildren?". This took me aback. I don't think anyone in the nursing profession should ever say that to a patient. That sticks in my mind, especially now that I have 4 grandchildren.

30. In terms of my understanding of the side effects at the time, I had been told that it may feel like I had got a bad dose of the flu, and that it would wear off after a couple of days. In fact, when I began the treatment in

September 2006 we timed it so I would take it on a Friday, thinking that I would back to normal by the coming Monday for going back to work.

31. There was no mention of depression or any psychological side effects.

32. The medication itself was awful, it was like ingesting bleach. I became desperately ill. It was like a horrendous strain of flu, I had the shakes, shivered uncontrollably, experienced nausea and mood swings – it was horrific. I struggled to even get out of bed, I struggled to go to work. I was restless and my sleep pattern was completely disturbed.

33. Psychologically it was bad. They only offered me antidepressants, and sleeping pills, and I just cried and cried in the clinic when they asked me how I was tolerating it. You wouldn't wish it on your worst enemy.

34. During the treatment I had to go back fortnightly, and in December 2006 they told me that because of my side-effects, and because there had been no improvement in the viral load, there was no point continuing the treatment, so I was taken off the drugs. It had not been effective - no one had ever told me that it wasn't 100% effective or even that there was a possibility of it being unsuccessful Perhaps I was naïve, but I thought the treatment was to clear the virus and at no time do I recall them saying there was a chance it would not work.

35. Exhibit WITN3768004, a letter dated December 2006 from Doctor GRO-B shows that the treatment was ineffective. The same letter and Exhibit WITN3768005, a further letter from GRO-B in August 2010, interestingly both refer to the fact that my liver disease was in fact very mild. These results were known from my biopsy in 1997 – should such a severe treatment be administered to someone with a mild liver disease?

36. They also told me that there would be new treatments available soon, and these are referred to in the letters in my medical records. I have never been contacted about any of these new treatments. Why I wonder? I also wonder why, knowing the potential side effects of the

interferon, did they simply not wait a little while for the new medication. Is it the cost? Is it numbers?

37. I remember that on the Christmas day of the year I finished the treatment, so 2006, I felt so dreadfully ill that, while I managed to cook Christmas dinner, as soon as I finished cooking I went straight to bed and couldn't enjoy the day with the family.

38. I had never felt so drained, so awful in all my life. I thought, "this can't be right?", because I had stopped the medication and by then, should have begun feeling better.

39. An appointment with my GP (January 2007) resulted in a blood test which showed that my thyroid levels were at rock bottom. The levels were so bad that the Dr showed her partners in her practice. They agreed that it was so bad they were amazed I was still standing up.

40. The diagnosis was that I had hypothyroidism. I was prescribed levothyroxine, which is a manufactured hormone used for an underactive thyroid. Hypothyroidism can cause depression, 'brain fog', fatigue and weight gain and I've been on antidepressants since I started on levothyroxine. The Levothyroxine levels and my thyroid require ongoing monitoring meaning they sometimes need to raise or reduce the dosage depending on the results of my blood tests.

41. My antidepressant, Fluoxetine, is adjusted too, several times a year.

42. I am now aware that the treatment of pegylated interferon and ribavirin can cause damage to your thyroid. I believe that the treatment for my HCV caused this damage to my thyroid, although no one has ever told me about or confirmed the link between the treatment and thyroid damage, I had to search online to find that out myself.

43. Soon after my Interferon treatment was stopped I was called back into the clinic for a blood test to monitor my condition. For some reason, I was never called again. It was only after about 2 years I remember

thinking; "no one has contacted me and asked me to attend clinic", there is nothing in my records, no letter asking me to come back, no one ever recalled me.

44. I think 2011 was the last time I attended the clinic. I had my annual blood test at my local surgery in September just gone, (2019)

45. I asked my GP GRO-B, earlier this year about my HCV and thyroid, and she told me my LFTs are fine, so I came away thinking nothing has changed in that respect.

46. I do suffer from a number of joint issues I am aware that joint problems can be a side effect of the virus.

47. At this moment in time I do not appear to be showing any adverse side effects or symptoms.

48. If they offered me more treatment with the drugs they have now, I don't know whether I would accept. it. I don't know anything about them. Once you are on the treadmill again, it's difficult to get off. Even if I was offered something by a consultant, I would be wary. I don't know if it would be worth me doing another course of treatment.

49. Since discovering that I have HCV, I have had to be very careful with precautions to ensure you don't infect anyone. I never tell anyone. Only my family know.

50. It's very hard to talk about it, I can't think about the time without getting upset. Prior to the treatment my teeth were ok, they were stable, but around the time I was finishing the treatment I noticed my teeth were deteriorating. 3 months after finishing treatment my crown fell out. I had no problems with it before and the deterioration continued with the enamel on my teeth starting to come off.

51. With the loss of my crowns and bridge, which eventually went, it's been recommended I have 3 implants, but when the dentist submitted his prices, it was going to be £9,000.

52. I took care of my grandson while managing the treatment, and it was very difficult to cope. I was exhausted the whole time. At that time my parents were aging, and I'd have to leave work to drive to Liverpool to see my father in hospital, and then rush back to look after my grandson. At times I'd have to go to Liverpool to stay with my parents for a week or two at a time to provide care for them. It was so hectic. I'd get home and go to bed and wonder when it was all going to end. But it did.

53. Now I find it very hard to go see a Doctor, I have to be really unwell before I will go. I know it isn't their fault, because I've never been mistreated by them, and I suppose they thought they were doing what was best at the time, but they must have known that the treatment was not guaranteed and that the symptoms were going to be more than a brief bad flu.

54. Our entire family hasn't trusted the NHS since then. I wouldn't give blanket authority for another transfusion. I would need to know a lot more about my options. My daughter has had NHS treatment, but does not trust the NHS and would go via private health care to avoid the NHS if possible.

55. My husband became ineligible to donate blood after my diagnosis, something he had always done. He was told that he was ineligible because of his wife being infected with Hepatitis.

56. None of my family have been offered testing to establish that they are in the clear from HCV and neither has it been recommended to myself or to any of them individually that they get tested.

57. Perhaps it's to do with having GRO-B as a child, but you've got to make the most of it, so I put it to the back of my mind – it's better to get on with it,

you sort of forget about it until something happens which brings it all back.

58. I don't think we have suffered a financial loss, as while it was very hard, I was able to keep working and I didn't have to take unpaid leave. I was able to take either sick leave or holiday allowance when I needed to. There may have been some losses but it wasn't a great amount.

59. I haven't had any issues in obtaining any type of insurance because of my HCV status.

60. Our social life has not been greatly affected as HCV was never discussed and is not known about outside of the immediate family.

Section 6. Treatment/Care/Support

61. I have never had any difficulties in obtaining treatment due to my HCV status. Nor have I felt that I have been treated differently or stigmatised through having the HCV infection.

62. I had an operation on my foot in 2012, and I had to tell the consultant then. I've also told the dentist and it wasn't an issue for either of them.

63. I have never been offered any counselling due to my HCV infection or its treatment. Even when I was crying in clinic due to the side effects of the medication and was ripe for the offer of counselling, there was nothing – just pills, antidepressants, which no one wants to take if they can help it. At no stage were any of my family offered this service either, despite what they had to endure.

Section 7. Financial Assistance

64. My GP GRO-B put me onto the Skipton Fund. I applied for and got a lump sum payment of £20,000 and that must have been in 2007, I don't remember much about the application process or what had

to be done – I just remember that the Dr had to fill out some forms, as did I.

65. I recently read about the possibility of getting a monthly allowance, I hadn't heard of it before. The England Infected Blood Support Scheme, EIBSS, manage that now, so I got in contact with them and was given and filled out the forms – it was quite straight forward.

66. I was sure that I was going to be denied, that for some reason I would ineligible, but I was eligible and I'm now receiving monthly support payments which work out at £18,000 per annum, I was very surprised when I found out I was eligible. The monthly payments that I had missed out on were backdated to April 2016 too.

67. Other than my GP in 2006, no one has told me about the support funds that were available, and I did not know I was entitled to a regular income payment. We were certainly never informed that there was ongoing financial support.

68. I would like to say that when the Skipton Fund changed over to the EIBSS I was never informed. I've never moved house nor changed telephone numbers, so I know they haven't tried to contact me. I should have been told. How many others have missed out on what they are entitled to simply through not being aware or being made aware?

69. I have not been involved in any litigation in relation to my HCV infection or received any other financial support.

Section 8. Other Issues

70. I feel sorry for those who could not access their medical records, some of their experiences from what I have seen, have been horrific.

71. I think someone should be held to account for it. They knew it was happening and they did nothing. They must have known the scale of it

and how many people could be potentially infected, and still they did nothing. Each successive government has done that, too.

72. It has been very slow to gather momentum, slow in that no public inquiry has been properly handled until now. It is unbelievable that it has been left with no accountability this long!

73. There must be a lot of people that are still undiagnosed simply because it has not been handled properly.

74. I have signed the consent form for the use of my statement on the basis it will not be submitted until such time as my written statement is signed by me.

<u>Statement of Truth</u>

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

Signed .. GRO-B ....

Dated 29 April 2020