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Witness Name: **GRO-B**

Statement No: WITN0248001

Dated: 5th February 2019

INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12th December 2018.

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

Section 1. Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** 1957 and my address is known to the Inquiry. I am a retired medical laboratory assistant.
2. I intend to speak about my experience being told that I received contaminated blood after the birth of my daughter at Portway Hospital in 1982. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.

Section 2. How Infected

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3. In 1982, after the birth of my daughter, I had a retained placenta which had haemorrhaged. I was told that I required four units of blood to replace what I had lost. I was not asked whether I wanted the transfusion and I was not made aware of any associated risks.
4. I went home after the surgery and assumed that everything was fine. I didn't hear anything about the risks of my transfusion for years. The government must have known about it because it was all over the media a few years later.
5. I went through years of unexplained fatigue, going back and forth to the doctor and having blood tests. I didn't know why I was feeling so tired. It was not until 2016 when I found out that I had been infected. I went to the doctor because I was feeling unwell. I was having breathing issues, extreme tiredness and I felt low. I had a full screen of random blood tests taken and the liver function results came back funny. The doctor decided to do a hepatitis screen test for hepatitis B and C. It came back positive for hepatitis C. The doctor informed me of the results over the phone. I felt fine about this as I had discussed many matters with him that way. He asked me how this had happened. He asked me if I had piercings or tattoos, which I hadn't. Then he asked me if I'd ever had a blood transfusion, to which I said 'yes.' He said 'that's where you've got it from then.' I carried the virus for 34 years and I didn't know about it.
6. After seeing my GP I was referred to a liver specialist, Dr Jupp, at Dorset County Hospital. At the appointment I was provided with basic information about what hepatitis was, how it affected my liver and that it was the type which could be cured.
7. After learning I was infected, I never saw Dr Jupp once. I was always treated by liver nurses. I felt it was bad that I never saw him. I was still a liver patient and it was a big shock to find out I had hepatitis C. If he saw

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me once it would have helped, but he didn't. I was just given some leaflets and they didn't have time to speak to me properly. The nurses were sympathetic but I feel that I should have seen a consultant, have him sit down with me and go through it. The nurses didn't know the answers to everything, they would say 'hold on, let me ask Dr Jupp.' I had to sit there worrying while I waited for an answer.

8. I was not given a lot of information about the risk of transmission to my family. I asked the nurse and she said 'oh well just get them tested.' I think this could have been dealt with better.

Section 3. Other Infections

9. I don't believe that I have received any infections other than HCV.

Section 4. Consent

10. I wasn't given adequate information about the risks of the transfusion. The source of the blood was not revealed. I assumed it was from here. I didn't realise until years later that it came from America.
11. I was tested with my consent and I knew what they were testing for.
12. When I was diagnosed with hepatitis, I was told 'you're going to have this treatment' and that was that.

Section 5. Impact

13. I was depressed. I didn't want to do anything; I couldn't be bothered. As the years progressed there was constant tiredness. Depression was brought on by tiredness. I couldn't understand why I was so tired. I had blood tests during that time and nothing showed up. I had anti-depressants

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on and off for 34 years. I didn't stay on them long term because I don't like to do that. I felt really low in myself. I also had bad anxiety, I felt very anxious about most things.

14. When I found out about the hepatitis I was shocked and very upset. I cried a lot because I felt horrible.

15. I had a flare up with an underactive thyroid. I read articles that it can be attributed to hepatitis C. I also had an abnormal liver and a bit of cirrhosis. I was diagnosed with breast cancer in 2009. I don't think I would have got that if I didn't have hepatitis. It raised questions in my mind. I was really concerned. I had already been infected by 2009 with hepatitis, so I didn't know. No one else in my family has ever had breast cancer so I think there could be a connection. I am now in remission and I have mammograms every 18 months.

16. I worry about what the long-term impact this is having on my body. I don't feel 100% well even now. I'm always worrying to see if anything else will flare up.

17. The treatment was horrendous. I was given Interferon to self-inject into my stomach. I also had Ribavirin. It was the worst six months of my life. It was horrible.

18. I was put on the old treatment. I could have had better treatment that wouldn't have made me so ill, but I wasn't able to due to the cost. I had to suffer because of money. After three months I was getting ill. I was told I could stop treatment, but I would have to go on a waiting list in order to get the easier treatment. The nurse told me that if I had had that particular treatment I would have been able to carry on working. I was told to try the original treatment first to see if I could manage it. The 'new' treatment had less severe consequences. I believe that I was not offered that because of

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cost and the one year waiting list. I just wanted to get it done so I battled through it.

19. I was severely anaemic, tired all the time, dizzy, had nausea every day and my hair started to fall out. I couldn't eat much so I lost weight; I spent six months laying on the sofa. My husband had to go to work so I was alone all day. I was frightened to do much as I was scared I would fall over. I just spent six months vegetating at home.
20. I had to tell the dentist about my hepatitis because I was due for a checkup. He was happy to treat me, but I felt like a bit of a 'leper'. He said I had to come at the end of surgery so that he could sterilise the equipment. I felt the stigma.
21. The main impact on my family, was worrying that my daughter had the virus transmitted to her through my pregnancy. I had her and my husband tested. The results came back negative, but I felt bad that I could have infected them. It also impacted on my marriage; I was too tired to be intimate. It caused problems.
22. My family were all upset. My daughters were the most upset because they were worried about the treatment and whether I would be ok in the future. It was a big strain on my family for six months. My husband would do everything for me. He would go to work all day, then come home and cook. Being in a vegetative state for six months was horrible. I spent all day alone. It was such a long day every day with all sorts of things going on in my head.
23. The illness didn't create a strain on my relationship with my husband, I told him straight away. I was worried about telling my children. My girls are panicky, they get very upset and distraught. I told them immediately because they would have been hurt if I didn't share it. They were so

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distraught they didn't know what to do with themselves. Only my family know about my illness, I haven't told anyone else.

24. I was completely dependent on my husband. He was always at work, concerned. He would keep ringing to see if I was ok. It impacted on his job as he was always putting his thoughts about me, first. I had to ring him up twice asking him to come home; I was so ill that I didn't want to be left alone.
25. It had an impact on everything we did. We were always lively, biking, going out on our boat and fishing. My husband would take the kids to the beach when they were younger, but I would never feel like going. He felt frustrated because at that time we didn't know that I was actually ill. Physically no one could see the virus. My husband thought I looked ok and couldn't understand what the matter was. Looking back, he feels guilty not knowing that I was really ill. I couldn't go out and socialise more at night, because I was always too tired to do that.
26. I used to work at GRO-B microbiology lab. I was there 17 years. After my diagnosis, I couldn't work for six months. I couldn't even stand up. The NHS did give me sick pay, so finances weren't so bad. My husband had to take time off work to take me to the hospital.
27. My husband works for the NHS as well. We both know everybody; everyone was asking what I was doing and why I was off sick. I had to change my name when I was having blood tests as I worked in the same laboratory as where the testing was undertaken. I'm a very private person; I didn't want people knowing I had the virus. Everyone was always trying to fish for information. I found it very difficult.
28. Over the years of my working life at the NHS I struggled. I had a lot of time off due to sickness because I was exhausted, picking up lots of little

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things because my immune system was compromised. I was taken to HR and had warnings for being off sick. It was embarrassing and stressful at the time because I didn't know what was going on. It was really humiliating for me to receive written warnings. It's humiliating when your work colleagues know you've been carted off to HR, thinking 'she's been off sick again.'

29. I am not working now. I went back to work and decided to take early retirement. I still didn't feel well and I hadn't recovered from the treatment. I went back to work and caught a bad cold. I was really tired when I came home and I was struggling.

Section 6. Treatment/Care/Support

30. I was not supported well during treatment. I just had appointments, nothing else. There was no counselling or psychological support. If that was available I would definitely have been interested. I had to arrange my own counselling off my own back. I lost all my confidence and I was very anxious.

Section 7. Financial Assistance

31. I received £20,000 as a one-off payment from the Skipton fund in 2017. The liver nurse told me that there was financial assistance available. There were difficulties in applying. I had to fill out the forms and get the liver nurses to sign them, confirming that there was an impact on my life. They agreed that the hepatitis was the cause of my problems. It was stressful waiting to see if the nurses would back me up and if the consultant would sign the form. It was one trauma after another.
32. My GP had to ring the hospital to find evidence of the transfusion. The hospital is no longer there and the records have gone. I was distraught

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because I thought that if I go to the doctors and they have no record, how will I prove it? It was me doing all the running around. Luckily my doctor still had paper notes. I had to find it in my medical records, take a photocopy and send it to the Skipton Fund. Otherwise, they wouldn't have believed me. It's disgusting; it's not something you would make up. It was distressing having to prove my illness. It was traumatic. I didn't know at the time if they had the information, thinking 'how on earth will I prove I had this transfusion?'

33. I was given £253 month after that. I now get £1,500 a month since last year. I applied for a 'top up' payment and I received a letter one day, asking to scrutinise my husband's income. I thought 'crikey' because we are not wealthy by any means. I thought, what's it got to do with my husband's earnings? My husband saw red and started investigations. He got hold of Leigh Day Solicitors to see if I had a case against the Government and the NHS. Leigh Day said that I had a possible case but are yet to confirm whether they are taking me on as a client. I am currently unrepresented. Regardless, I sent the form for the 'top up' payment back and refused to disclose what my husband was earning. I didn't receive the top up. I felt angry because why should they base the increase of money, which I deserve, on what he is earning? It shouldn't matter.

34. The compensation was not anywhere near enough for what I've been through. Not for carrying this for 34 years. I want accountability. The Government, from what I gather, knew that blood from America was infected but they carried on using it. I should have been compensated like you would with any other personal injury or negligence case. I'm paid in 'drips and drabs' at the moment. If I was given a proper one-off payment, I could have decided what to do with it.

35. There were no preconditions imposed on the grant of financial assistance. If there were, I wouldn't have applied.

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Statement of Truth

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

Signed

GRO-B

Dated

13/2/19

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