Witness Name: GRO-B
Statement No: WITN3507001
Exhibits: WITN3507002
Dated: November 2019

# INFECTED BLOOD INQUIRY

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## FIRST WRITTEN STATEMENT OF GRO-B

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

## Section 1. Introduction

1. My name is GRO-B. I was born on the GRO-B 1950 and I live at GRO-B GRO-B with my wife of 40 years, GRO-B. We have two sons who are 37 and 39. I am a retired GRO-B GRO-B

2. I was infected with Hepatitis C (Hep C) as a result of contaminated blood transfusions.

3. I make this statement without the benefit of access to my full medical records.

## Section 2. How Infected

4. In or about December 1986 I started getting really poorly. I went to see my GP and was referred to go and have a blood test at Hillingdon Hospital. When the results came back the doctors found that my platelets in my blood were below normal level. I was told to go back to the hospital and I was transfused with 3 units of plasma to boost my levels.

5. I was later tested to see whether my platelets had increased, but it appeared they hadn't. This meant I had to have a bone marrow extraction. I struggled to get back to work for a period of time after this, but did eventually return full-time.

6. As a result of the above blood transfusion, I was infected with Hep C. This was the only blood transfusion I ever had. The only other times that I had really been poorly was when I had my appendix out in 1965 and in December 1985 when I referred to my GP but no further action was taken. I did not require blood products on either occasion.

7. Prior to having the blood transfusion I was given no information or advice about the risk of being exposed to infections.

8. I believe I was tested for Hep C in 1987, previously known as Non A Non B Hepatitis. I remember having a blood test, because I was getting poorly again. I was called into the doctor's office and asked by Dr GRO-B '*do you want the good news or the bad news first*'. He was very cocky about it all. My wife was with me at the appointment and we asked for the bad news first, and he relayed what had happened and that I was infected with Hep C. There was a nurse in the room but we never got her name. When we left the room she ran after me, embraced me and told me how sorry she was.

9. Dr GRO-B used to attend GRO-B in GRO-B which my family also attended. I remember seeing him at my son's confirmation; I was so angry I could have hit him.

10. I questioned how I was infected, and I was told it was through the platelet transfusion I received. Dr GRO-B told me I couldn't sue him, but I could sue the hospital. I asked what he was going to do about it and he just shrugged his shoulders at me.

11. I had no information relayed to me about the risks of Hep C. This was the 80s, I couldn't mention it to anyone, it was a taboo subject.

12. The severity of being infected hit me as soon as they told me, it was a big shock. I was always a worker and never taken days off sick and worked 6 or 7

days a week. I found out how dangerous the infection was by Dr GRO-B, my GP. This wasn't until about 2 weeks after finding out I was infected. My wife was told not to touch my towels. She was also told if I had a bleed she wasn't to touch me and anything I used to eat or drink should be sterilised. The doctor warned my wife that she should consider leaving me. This was quite upsetting to hear.

13. I do not believe I was given adequate information of how to manage the infection, but I think it was because there was so little information about Hep C at the time. They knew the disease existed but they just didn't understand it as much. There was no one to turn to at the time.

14. I feel that information should have been communicated to me earlier. The way the information was communicated to me was shocking. We were treated like lepers.

## Section 3. Other Infections.

15. I do not believe I was infected with anything else other than Hep C.

## Section 4. Consent.

16. It was possible that I was treated and tested without my knowledge and consent because nobody told me that I was going to be tested for Hep C.

17. They used to regularly take blood from me after I was found to have Hep C.

18. I believe they were just doing what they wanted to do. They never told me that they were testing me for Hep C, I was just told of the infection. They asked if I was promiscuous and made out that I was gay or a drug user. They tried to put the blame on me.

19. I believe I was treated and tested for the purposes of research. I know a vial of my blood was sent to Kings College Hospital (KCH) for research.

## Section 5. Impact

20. We never knew the outcome of what was going to happen, I was sure it was a death sentence. As stated above, my wife was told to leave me at the time.

21. My wife knows more than I do in relation to the infection as I shut down and didn't talk about it. I blocked myself off from other people. I felt like I couldn't turn to anybody, my wife and I only had each other. It made us very tight knit. We relied on each other, and that's all we had. We couldn't even tell our kids as they were so young at the time.

22. I still recall the kids coming home from school on the day we found out I was infected. I felt I couldn't cuddle them or kiss them. I distanced myself from the kids. I had to make sure they wouldn't be infected. I tried my best to stay as active as possible, trying to keep up with my two sons but it became very difficult.

23. Physically I was washed up, always tired. Between 1984 and 1987 I hadn't had a single day off work sick, but suddenly I was tired all the time and drained from it all. I was yellow from jaundice; it was clear there was something wrong with me.

24. Being infected with Hep C massively affected my liver, and I was diagnosed with cirrhosis as a result. I cannot recall when it was exactly, but I believe it was the early to mid 1990's that I started treatment of Interferon and Ribavirin, which I was given at St Mary's hospital (SMH), but it failed. I started going further and further down hill after the first course of treatment failed. I was under the care of Dr Foster at SMH, who was on the panel for the Skipton Fund, and GRO-B was the nurse that looked after me.

25. I remember Dr GRO-D took over my treatment at SMH in or about GRO-B GRO-B. I was so poorly at the time, and I was told there was no hope for me. I recall my wife arguing with Dr GRO-D, asking what he meant by 'no hope'. He told her that he wasn't talking to her, but he was talking to me. I told him that I wanted a second opinion, and Dr GRO-D tried to tell us there was no time left to get any other opinions.

26. Dr GRO-D said he could write a letter to Addenbrooks Hospital (AH) about having a transplant, but he said 'in his opinion it was too late'. My wife begged him to write the letter, which he eventually did. We went up to AH to see a Dr Allison about 2 weeks later. I had about 4 pillows in the car because I could no longer sit up straight. I was being sick into a bag the entire journey. When we got to AH I had to sit in a wheelchair; and a nurse was fussing over me telling me that I was going to be alright although I think she was just trying her best to be kind. When I was called in to see Dr Allison he pulled me into another cubicle and then took me straight into the ward. He told my wife 'Don't worry, we'll save him'. I was told I only had 5 weeks to live. I was given an intravenous treatment to help my liver, which helped me a lot. I was then sent home with a pager, and I was told that if it went off it meant that a liver was available. 5 weeks later I had a liver transplant. This would have been about April 2003. This liver transplant was not successful.

27. In 2007 I needed another transplant. GRO-B GRO-B. This cleared the virus in 2014. I was called in for a programme which I was told would either 'make or break me'. I volunteered for it, because I wanted to clear the virus. I was a guinea pig. It was very intense, I was told that if it worked it would really work but if it didn't it would be catastrophic.

28. After the second liver transplant I had complications. I ended up having a tracheotomy. I had to have about 20 litres of blood.

29. The only thing that they gave me a hint about it being experimental was that certain counties wouldn't pay for the treatment. GRO-B was one of the counties, and there was a delay in starting the treatment because of the funding.

30. During the first course of Interferon and Ribavirin I had bad side-effects. I suffered with 'Ribavirin rage'. I would get so angry and short tempered and I would start to shiver. Mentally I was in a terrible place. I shut myself off. I had a good appetite but I wouldn't eat a regular meal. I couldn't deal with some

cooking smells; it would make me physically sick. I would shiver and shake all night, and had flu like symptoms. I think this was as a result of the treatment.

31. When I had the second course of treatment, the symptoms weren't as bad as the first course. It felt a lot more like being in withdrawal. I think by this point we knew what impact the treatment would have on me, and my wife and I knew what was coming and were able to prepare for it.

32. Being infected with Hep C didn't have much of an impact on my dental care, or any other care. I refused to go to the doctors and the dentists. I was so concerned of the stigma that was attached to it at the time. Every blood test I had had a hazard sticker on. I just didn't want to explain myself to everyone. I felt dirty even though it wasn't my fault but I was thrown in a barrel of mud. The world outside was normal but I wasn't anymore.

33. The stigma had a big impact on our family. We never told my mother-in-law what was happening but she put two and two together. When my wife used to go and see her mother she used to give her a 'special cup' to drink from.

34. We were cut off from our family because we couldn't tell them. We told our sons when they were a little older. They were our strength. They always said they didn't care and they still loved me. They had to be tested as well for Hep C, which was negative. It was distressing because they were still so small.

35. Whenever we got invited out with people we used to have make excuses not to go. My social life was therefore affected. Only my wife and I would go out alone. If I cut myself, there was always a fear of trying to sort it quickly. I didn't want anyone to touch me.

36. I remember when I had an accident at work, and a drill went through my finger that I had to act quickly, I didn't want anyone to touch me or help me. I needed to make sure that I cleared up the blood. The nurse, GRO-B at my workplace knew that I had the infection. She was the only one who knew what was going on in the company.

37. My wife had to have counselling due to what happened to me. She was meant to only have 6 weeks of treatment but it ended up being 6 months.

38. The Hep C did affect my employment. I tried to maintain my job, but I just wasn't as fast as I used to be. Everything my job entailed was experimental, working out the best ways to put a GRO-B together. I could have progressed within the company, but I believe being infected with Hep C held me back.

39. In or about 2005 whilst I was in the hospital I got a letter from my employer which stated that my contract had ended. We had a meeting about it, but their attitude was that I was no good to them anymore. I worked there for 21 years and I felt like they just kicked me out. Not once in 2 years between 2003 and 2005 did anyone even come and see me at the hospital.

40. My wife had a GRO-B and I worked there for a while, but I stayed away from people. I was always worried that I would cut myself. Instead I kept to myself and made sure all the paperwork was done at home. The job didn't pay me any wages at that time. I started to receive a some wages in or about GRO-B, GRO-B. I had no regular salary at the GRO-B as I couldn't work for long periods of time.

41. It has definitely had an impact on my family. My sons don't want to talk about it, and I know that they worry about me a lot. I don't think it will ever end; it will always be an ongoing worry.

42. My wife has GRO-B and I believe it has got worse after finding out about my diagnosis. She has a severe fear of needles and she always had to have blood tests. She has been through a lot with it all.

43. My mother-in-law has dementia now so she doesn't remember, but she used to watch the adverts on the TV and shout about it all, saying 'we never want to go near people like that'.

44. The impact has been catastrophic. It's a lifetime of pain which can never be erased.

## Section 6. Treatment/Care/Support

45. I did receive difficulties receiving treatment, care and support. It wasn't until I was referred to AH that I received any form of real care and support. The nurse and doctors I saw there would always look after me. They treated me like a son.

46. I was not offered any form of counselling or psychological support. I do not know if it would have helped had it been offered to me, it's too hard to say. I try to just think about the present not the past. I just shut myself off from it all.

## Section 7. Financial Assistance

47. I first applied for financial support 3 years ago and it was denied on the grounds that we have no medical records to prove that I was infected as a result of a blood transfusion, copy letter from the EIBSS is exhibited at **'WITN3507002'**. I initially tried to apply for my medical records over the phone from Hillingdon Hospital. However, I was told that they are no longer available and they been destroyed. It was a stressful process.

48. I am in the process of formally applying for my medical records from all the hospitals that I have been treated at.

## Section 8. Other Issues

49. Between December 1986 and March 1987 I was referred by Dr **GRO-B** to Hillingdon Hospital by letter. I was due to see Dr **GRO-B**. Subsequently, the letters that were sent from the hospital referring me to Dr **GRO-B** were destroyed. It seems peculiar that I was contacted and sent for an operation at Hillingdon Hospital without any contact or correspondence. Supposedly these had been destroyed, which has been recently confirmed by Hillingdon Hospital. I have been told that all my records prior to 1990 are no longer available to me.

50. There were costs implications when I was in hospital. The first time I was in hospital it cost us approximately £2,500 so my wife could stay near the hospital

51. My brother-in-law was a haemophiliac who was infected with Hep C. I do not know if he was infected with HIV or not. I don't know if anyone is fighting for him, but I would like to bring attention to him as well.

52. My wife and I always wanted more kids, but it felt like the choice was taken away from us. We had no idea whether we would pass the infection onto the child. We decided it wasn't worth the risk. Our marital life became non-existent, and put a huge strain on our relationship.

53. I always ask what I did wrong to deserve this. It not about the money but somebody should be held accountable for what has happened to us.

## Anonymity, disclosure and redaction

54. I wish to remain anonymous.

55. I would be willing to provide oral evidence to the inquiry.

## Statement of Truth

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

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

Dated 6 - 11 - 19 ......................................